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Changing Lives:

The Impact of a Child's Brain Injury on Maternal Ideology

by

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of MASTER OF EDUCATION

Edmonton, Alberta

Fall 1995

Echoes of each other's being.

Whose eyes are those who look like mine?

Whose smile reminds me of my own?

Whose thoughts come through with just a glance?

Who knows me as no others do?

Who in the whole wide world is most like me

yet not like me at all?

My sibling.

From What Makes Us Siblings (Faber & Mazlish, 1989, p. 114)

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Changing Lives:

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A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment

of the requirements for the degree of **MASTER OF NURSING**

Faculty of Nursing

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Faculty of Graduate Studies and Research

The undersigned certify that they have read, and recommended to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled **"Changing Lives: The Impact of a Child's Brain Injury on His/Her Siblings"** submitted by **Angela E. Weir** in partial fulfillment of the requirements for the degree of **Master of Nursing**.

DEDICATION

To my daughter, Laura, whose courage and determination are an inspiration to all who know her. We are very proud of you.

Abstract

This grounded theory study presents a theoretical analysis of twelve siblings' experiences of living with a brother with a brain injury. Through two tape-recorded, semi-structured interviews, siblings described their experiences and perceptions about living with a brother with a brain injury, which were analyzed using the constant comparative method. The basic social psychological process that emerged from the data was "changing lives." Following their brother's injury a sibling realizes that his/her life is changed as normal routines are disrupted and roles and relationships change. A sibling makes adjustments to cope with these changes. A combination of adjustment strategies are employed: distancing, seeking support, altruistic helping and emoting. Positive experiences of closer relationships and improved family communication allow a sibling to decide to get on with his/her life by putting the changes into perspective. Less positive experiences of more strained relationships and little communication leads to a reluctant acceptance of his/her changing life.

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CHAPTER I

INTRODUCTION

Approximately 500,000 individuals in Canada annually suffer brain injuries (Acorn, 1993). The Ontario Brain Injury Association estimated that for the year 1995 the incidence of pediatric traumatic brain injury (TBI) in Canada (age 0 to 15 years) was 9051 children (per personal communication February 13, 1997, Jennifer Button, Ontario Brain Injury Association). The National Head Injury Foundation [NHIF] Pediatric Task Force reported that, in the United States, 220/100,000 youths under age 15 will sustain a brain injury each year and that brain injuries to children between birth and 19 years of age annually result in 30,000 children becoming permantly disabled (Savage, 1993). Although TBI is the leading cause of death and disability in children and adolescents (Goldstein & Levine, 1987) as a result of improvements in before-hospital care, medical transport, and intensive medical-surgical management in the past few decades, increasing numbers of children with a brain injury are being returned to families ill prepared to provide for their ongoing rehabilitation needs (Jaffe, Brink, Hays, & Chorazy, 1990).

A child who experiences a traumatic brain injury (TBI) is in many ways forever changed and continually challenged. But it is not only the child who is changed and challenged - the lives of the family who love that child are also forever changed (Singer, Glong, Nixon, Cooley, Kerns, Williams, & Powers, 1994, p.3).

As nurses increasingly recognize the importance of the family, the needs of the

well siblings as a critical component of the family system, have become more important. Although a considerable body of literature investigating the formative significance of sibling relationships exists, siblings are often overlooked in family research. Researchers report that siblings have a major influence on one another's behavior and development (Cicirelli, 1995; Powell & Gallagher, 1993; Teti, 1992; Stoneman & Brody, 1993), often independent of the influence of their parents (Cicirelli, 1995). Their special relationships provide a context for social development and are a foundation from which brothers and sisters are prepared for experiences with others outside the family system (Abramovich, Corter, & Pepler, 1980; Abramovich, Corter, Pepler, & Stanhope, 1986).

Studies of the impact of chronic illness and/or disability on well siblings have generally focused on the individual sibling characteristics and variables (i. e.; birth order, gender, age spacing, family size) and their relationship to psychological adjustment (Labato, Faust & Spirito, 1988). Most research on chronic illness/disability focuses on hardships imposed by the illness and how individuals and families manage these hardships. Unfortunately, there has been less emphasis on how well siblings view chronic illness in their own lives (Gallo, Breitmayer, Knafl, & Zoeller, 1991). Several authors have noted that parents of children with chronic illnesses may not accurately perceive how their children are coping (Stoneman & Brody, 1990; Haverman & Eiser, 1994; Walker, 1988), which reinforces the importance of understanding the impact of a brother or sister with TBI on the sibling from the sibling's perspective.

Brain injury in children is similar in several ways to other chronic illnesses and disabilities in childhood in relation to its impact on the family, and some generalization

between the two is valid. However, childhood brain injury is unique in its social stigma, uncertain prognosis, and a wide variety of serious behavioral, cognitive, and physical deficits (Brooks, Campsie, Symington, Beattie, & McKinlay, 1986; DePompei & Zarski, 1989). Studies also indicate that the family's ability to provide support for the brain injured member is instrumental to the degree of his/her recovery (Birmaker & Williams, 1994; Brooks, 1991; Kozloff, 1987; McKinlay, Brooks & Bond, 1981; Oddy & Humphrey, 1980). To date, few studies have focused on the effect on children and siblings of brain injured survivors (Spanbock, 1992). Therefore, research focusing on children with brain injury and their siblings is necessary in order to increase the more general understanding currently available in the literature. Research examining the impact of brain injury to a child on family systems is one of five goals to improve services for school-age children with brain injuries and their families set by the Pediatric Task Force of the NHIF (Savage, 1993).

My interest in exploring the impact of a child's brain injury on their siblings is based on personal and professional experience. My daughter's TBI has provided me with a personal knowledge of the potential impact of a brain injury of one family member on every member of the family and has enhanced my professional growth and awareness. As a pediatric nurse with many years experience working with children and their families in critical care settings, I found the issue of the effect of a child's illness on siblings to be one seldom addressed by health-care providers. Additionally, when questioned about how siblings were adjusting, many parents admitted that they had not given much thought to the impact on the siblings.

Research Question

The initial research question for this study was: How does the experience of living with a brother or sister with a TBI affect his or her siblings?

Purpose and Rationale

The purpose of this study was to describe and gain an understanding of the impact of a child's brain injury on his or her siblings. The focus of this research is on the experiences of the siblings from their perspectives. The information gained through this study may enable nurses and other health care providers to anticipate potential difficulties siblings may experience due to the impact of the child with a brain injury on the family system and to promote positive adjustment of all family members.

Definitions

There are many overlaping terms used in the literature describing injury to the brain. These terms are often used synonymously but have different meanings. The following are two terms that are often found.

Traumatic brain injury is an acquired injury to the brain caused by an external force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance. The term applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions;

information processing; and speech (Blosser & DePompei, 1994).

Acquired brain injury [ABI] is a brain injury resulting from causes other than an external force and include: anoxic injuries to the brain such as hanging, choking, near drowning; infections such as meningitis and encephalitis; strokes; tumors; metabolic disorders such as insulin shock and liver and kidney disease; toxic encephalopy such as lead poisoning, mercury and other chemical agents (Savage, 1993).

For the purposes of this study the term brain injury will be used to include both TBI and ABI as described above. The term does not apply to brain injuries that are congential or degenerative, or brain injuries induced by birth trauma.

CHAPTER II

LITERATURE REVIEW

Studies described in this literature review cover four areas of research: sibling development, siblings of chronically ill or disabled children, the impact of brain injury on the family, and siblings of children with brain injury. The review of the first three areas is not exhaustive, but provides a sampling of the most representative studies. However the review of reported studies on siblings of children with brain injury is as complete as possible.

Families are interrelated systems that support the interdependence of individual family members. Each member of the family is a critical element whose personality and interactions affect those of other family members (Kleiber, Montgomrey, & Craft-Rosenberg, 1995; Powell & Gallagher, 1993). As one member of the family changes, so too, will the other members. Beckman and Bristol (1991) reported that the fundamental concept of a family system focus is the family consists of a number of interdependent subsystems, the sibling subsystem being one.

The Importance of Studying Sibling Relationships

Siblings have a major impact on one another's behaviour and development. This impact may be relatively independent of the impact of parents and other family members on the siblings, or the impact of the siblings on the total family system. (Cicirelli, 1995). Sibling relationships can be defined as

the total of the interactions (actions, verbal and non verbal communication) of two (or more) individuals who share common parents, as well as their knowledge, perceptions, attributes, beliefs and feelings regarding each other from the time when one sibling first became aware of the other (Cicirelli, 1985, p.180).

Sibling relationships possess attributes common to all interpersonal relationships but also have unique characteristics which enhance the strength of the sibling bond. The sibling relationship is: 1) normally the longest relationship that an individual will experience in his/her lifetime, 2) ascribed by birth (or by legal action, as is the case of step - and adoptive siblings), rather than earned, 3) one of close daily contact as siblings interact within the home, 4) one of relative egalitarianism in the majority of families, and 5) one which experiences shared as well as non-shared experiences which contribute to the siblings' individual differences (Cicirelli, 1995).

Siblings' special relationships provide a context for social development. Through their social interactions siblings learn a "give and take" process. They learn to share, help each other, learn to compromise, and learn about resolving differences. This socialization process has a profound influence on the life of the sibling (Powell & Gallagher, 1993) and is a foundation from which brothers and sisters are prepared for experience with others outside the family system. Family characteristics, including size, socio-economic status, and religion, appear to be important factors contributing to sibling adjustment (Dyson, 1989; Stoneman, Brody, Davis, & Crapps, 1988; McHale & Gamble, 1989). However, Stocker, Dunn, and Plomin (1989) demonstrated that the child's temperament, maternal behavior, and the child's age accounted for more of the variance in the quality of

sibling relationships than did family structure variables.

Two questions regarding sibling relationships have been explored, which will be addressed in the following section. How do relationships between siblings develop and how do they change over time through childhood and adolescence? What accounts for individual differences between siblings and their relationships?

Developmental Changes in Sibling Relationships

"A sibling relationship begins when one sibling first becomes aware of the other" (Cicirelli, 1985, p.180). Studies of very young siblings (Abramovich, Corter, & Lando, 1979; Abramovich, Corter, & Pepler, 1980; Abramovich et al., 1986) discovered that older siblings took a leadership role in sibling interactions, demonstrating prosocial behaviour as well as some aggression, threats, and struggles over objects with younger siblings. The younger siblings demonstrated a noticeable tendency to imitate their older siblings. Teti (1992) found that the older sibling develops social skills in interacting with the younger at this early stage of development, while the younger sibling develops cognitive skills by imitating the older sibling. As siblings increase in age, the younger sibling becomes a more active participant and the older sibling takes more interest in the younger sibling (Brown & Dunn, 1992).

The period from early childhood to middle childhood is a time of transition in sibling relationships (Cicirelli, 1995). As the older sibling enters school and develops peer relationships there is a reduction in sibling interaction. However the older sibling is able to help the younger sibling with school related problems when they are ready to enter school. At this stage younger siblings often ask an older sibling about topics that they feel

uncomfortable discussing with parents (Bryant, 1992)

Less is known about sibling processes during adolescence than during other periods. Buhrmester and Furman studied the sibling relationship process during the late childhood and adolescent years (Buhrmester, 1992; Buhrmester & Furman, 1987, 1990), examining qualities of warmth and closeness, status and power, and conflict. Same sex siblings reported greater warmth and closeness than opposite sex siblings. Conflict increased with closer age spacing between siblings. The power differential between siblings decreased as the older siblings were no longer expected to care for the younger sibling, resulting in a move toward greater egalitarianism in the relationships. Buhrmester and Furman (1990) suggested that although the changing social ecologies of childhood and adolescence may partially account for decreasing sibling interaction, they may also reflect the psychological transition from dependency on family to investment in peer relationships.

<div align="center">Individual Sibling Differences and the Sibling Relationship</div>

Individual differences exist between the characteristics (such as personality and cognitive characteristics) of siblings in the family and in the characteristics of the relationship between different sibling dyads (Cicirelli, 1995). As a result of evidence for the association between the quality of the sibling relationship and aggressive behavior, rejection by peers, early development of co-operation in play and aspects of socio-cognitive development, Dunn (1989) stated that the question of what factors influence individual differences in sibling's behavior is an important one.

Many early studies of sibling differences examined the effects of sibling birth

order based on the premise that the firstborn sibling received more attention and family resources than later born siblings. Other early research attempted to explain sibling differences by adding sibling variables of family size, relative age, and gender, to birth order.

Some sibling characteristics have been explained by the impact of critical life events on sibling development. Dunn (1984) argued that the life of a child is altered in a significant way by the occurrence of a critical life event. The child's response to their new world may change feelings, beliefs, and ways of acting and relating to others. Each family member's beliefs are developed through their interactions with each other (Wright, Watson, & Bell, 1996). Siemon (1987) explained that perceptions are the ideas that one develops about self and others based on experiences. Our beliefs and perceptions determine the way we feel and how we feel determines how we behave (Donaghue & Seigel, as quoted in Wright, Watson & Bell, 1996). Studies examining the impact of divorce on sibling relationships demonstrated varying results: from complete dissolution of the sibling relationship (Kaplan, Hennon, & Ade-Ritter, 1993) to the relationship acting as a buffer to the impact of the stress of the divorce (Kempton, Armestead, Wierson, & Forehand, 1991).

The association between child temperament and sibling relationships, which can influence the degree of hostility and conflict between siblings, has been studied by a number of researchers. Children who are active, intense, or unadaptable in temperament were found to have more conflictual relationships with their siblings (Boer, 1990; Brody & Stoneman, 1987; Brody, Stoneman, & Burke, 1987; Stocker, Dunn, & Plomin, 1989;

Stoneman & Brody, 1993). The match between the sibling's temperament is important. Siblings who both have an intense, and unadaptable temperament have a more hostile relationship (Munn & Dunn, 1989). On the other hand, Brody et al. (1987) reported that when one sibling with a difficult temperament is paired with an adaptable and easy going sibling, their relationship is less conflictual. The positive temperament of one sibling may buffer the relationship from the detrimental effects of a difficult temperament in the other sibling.

Some researchers have suggested that sibling relationships are in large part a function of the parent-child relationship (Brody et al., 1987; Teti & Abalard, 1989). Maternal differential behavior toward their children is a variable that has been studied to explain differences in sibling relationships. Studies observing maternal differential behavior and subsequent sibling interaction generally have revealed increased negative behavior among siblings (Brody et al., 1987; Brody, Stoneman, McCoy, & Forehand, 1992; Howe & Ross, 1990; Stocker, Dunn, & Plomin, 1989). Differential maternal behavior was associated with lower rates of all sibling-to-sibling behavior and associated with negative sibling adjustment when one sibling perceived himself or herself as the deprived or unfavored child. Dunn and McGuire (1994) emphasised that it is what the child perceives to be different that is important, regardless of whether or not both siblings are exposed to the same event. They add that, within the sibling subsystem, a given action by one sibling or parent, is perceived differently because it is viewed from each siblings own perspective. The significance of maternal differential behavior is underlined by the findings that emotional adjustment differences in adolescent siblings are associated with

perceived differences in parental behavior towards siblings (Daniels, Dunn, Furstenberg, & Plomin, 1985).

<div align="center">Summary</div>

Researchers have used many different theories and approaches to the study of sibling relationships. However, most studies have found that: the contribution of the sibling relationship to each other's development is significant; sibling socialization of one another can be independent of parental influences; there are long-range changes in sibling characteristics and changes in the relationships over time (Cicirelli, 1995). A critical life event such as the chronic illness/disability of a child in the family may significantly alter a sibling's life (Dunn, 1984). These findings demonstrate the importance of the sibling relationship which influences the development of each child within the family system and provide a foundation of knowledge from which to understand the impact of handicap or disability of a child, on their siblings.

<div align="center">**Siblings of Children with Chronic Illness or Disability**</div>

"Siblings relationships, normally critical to a child's overall development, take on special significance when one of the siblings has a disability" (Powell & Gallagher, 1993, p. 3). Simeonsson and McHale (1981) and Labato's (1983) review of early research studies (1960s and 1970s) reported that this body of literature focused on whether siblings were at higher risk for maladjustment or behavior problems and frequently described negative psychological effects of having a disabled sibling. Simeonsson and McHale reviewed literature examining the relationship between siblings and their disabled brother

or sister. A number of factors, either alone or in combination, was found to influence

sibling adjustment. Positive adjustment was associated with small family size, the sibling

younger than the disabled child, a male disabled child, sibling and disabled child of the

same gender, a severe level of impairment, and impairment of an ambiguous nature (eg.,

mental retardation). Factors associated with negative adjustment were large family size,

the sibling older than the disabled child, sibling and disabled child of different gender, a

mild level of impairment, and a visible impairment clearly defined. Overall, early studies

found that siblings with a disabled brother or sister frequently have problems of

adjustment and development.

Lobato (1983) focused on literature examining the effects, if any, of a

handicapped child on his or her nonhandicapped siblings in which most researchers

assumed that these siblings experienced more stress than most and, therefore, are at

greater risk for psychological problems. A related assumption was that because

handicapped children require more attention and resources on the part of the parents than

do normally developing children, siblings were more likely to suffer a lack of parental

attention or to be burdened by excessive childcare responsibilities. Lobato found that

there were few well-designed empirical studies that supported the assumption that, as a

group, siblings of handicapped children were actually at risk for or exhibited more

problems in psychological adjustment. As in Simeonsson and McHale's (1981) review,

Labato reported that the research revealed that certain siblings might be vulnerable to

adverse experiences, depending on such factors as sibling sex and birth order, family

socio-economic status, and parental reaction to the handicap. This research focused

almost exclusively on demographic variables and on the negative effects of the handicapped child on the normal sibling.

Since 1980 researchers have shifted from adjustment problems to examining psychological well-being (measuring adaptation and maladaptation). Review of this literature reveals both positive and negative effects for siblings of disabled children (refer to Table 1). Powell and Gallagher (1993) stated that the effects of a child with a disability on their siblings can be viewed in terms of a continuum, with very positive outcomes at one end, and very negative outcomes at the other. On the positive side, some siblings report benefits from learning to live and cope with the demands of a child with a disability. These siblings experience pleasure at the accomplishments of their brother or sister and develop an understanding and compassion for all people as individuals with unique needs and abilities. Negative effects reported by siblings include bitterness and resentment because of the extra attention given to the child with a disability. Others are worried and anxious about how to interact with the brother or sister, or felt guilty because of their own good health (Powell & Gallagher, 1993).

<u>Negative Effects</u>

A number of researchers reported results demonstrating increased psychological risks of depression, anxiety, and lower self-esteem. Ferrari (1987) examined potential risks to sibling's self-esteem. He reported that the siblings of diabetic children had lower overall self-concept scores than matched siblings of healthy children. Siblings reported special concerns in their perception of their intellectual and school status, personal happiness, and life satisfaction.

McHale and Gamble (1987) found that older sisters of children with mental retardation showed poorer adjustment in four measured areas (ie., depression, anxiety, self-esteem, and conduct problems) than did siblings of children without disabilities. Older brothers were also more anxious and had lower levels of perceived competence in the areas of social acceptance and conduct when they had a sibling with a disability. Negative effects for older sisters of mentally retarded children were also reported by Stoneman, Brody, Davis and Crapps (1987, 1988 1989). Multiple caretaking responsibilities by older sisters were associated with sibling conflict, and decreased opportunities for peer contact, and out-of-home activities.

A major source of stress for children is day-to-day conflict and difficulties in their relationships with family members. Gamble and McHale's (1989) study compared stress and coping between siblings of handicapped and non-handicapped brothers and sisters. Stressor frequency and affect correlated consistently with the assessment of the sibling relationship. The researchers reported stressors elicited from siblings as: physical and verbal aggression of the handicapped child, weird or strange behavior, disabled brother or sister enters room and takes things without permission, gets upset with a sibling for no reason, is hurt or sick, sibling has to baby-sit, clean up or help when he or she doesn't really want to. Since there is a large discrepancy of stress reported by parents versus that reported by the sibling it is important to identify stressful events from the point of view of the sibling (Royers & Mycke, 1995).

Breslau and Prabucki's (1987) longitudinal study of children with severe physical disabilities found that the siblings of children with a disability experienced increased rates

of psychiatric impairment; higher initial and sustained levels of aggression; and increased depression and social isolation over time as compared to the control groups. The largest increase in depression and social isolation were among siblings younger than the child with a disability. Tritt and Esses (1988) findings supported those of Breslau and Prabucki. They reported that siblings of children with a disability had significantly more behavioral and adjustment problems and were more likely to be withdrawn or shy than siblings of children without a disability.

Other studies also have reported that when siblings are expected to assume caregiving responsibilities for the disabled child, they may become isolated from their peers, at risk for educational failure, and feel angry, resentful, and guilty (Orsillo, McCaffery, & Fisher, 1993). Brett (1988) found that families of children with leukemia coped most often by "not talking about the illness", resulting in increased isolation from peers.

<div align="center">Positive Effects</div>

Contradicting past findings, other recent studies have illustrated that well siblings of chronically ill/disabled children do not experience a higher incidence of behavioral and social competency problems, and that these children may not be uniformly at higher risk for development of such problems (Faux, 1991; Gallo, Breitmayer, Knafl, & Zoeller, 1991, 1992; Menke, 1987). Families have reported that brothers and sisters gain from living with a disabled sibling (Begun, 1989; Faux, 1991; Gallo et al, 1991; McHale, Sloan, & Simeonsson, 1986; Rothery, 1987).

McHale, Sloan and Simeonsson (1986) compared the relationships of children and

their brother or sister with a disability to that of brothers and sisters without a disability. The researchers also examined the differences in the quality of relationships among siblings of disabled children. Siblings were interviewed about their relationship with their brother or sister, and their mothers completed a behavior rating scale to describe the positive and negative effects of their children's behavior toward each other. Both siblings and mothers rated the relationships positively. Further analysis revealed that the quality of the relationship between siblings of disabled children was not as highly correlated with status variables (eg. age, gender, family size) as with certain problems (eg. perceptions of parental favoritism, coping ability, and concerns about the future of the child with a disability).

Menke (1987) explored the impact of a child's chronic illness on siblings in the family system. Sibling responses were compared to responses of their parents. The parents reported few behavioral problems with the siblings interviewed. Older siblings voiced protective concerns for the ill brother or sister. Menke concluded that school-age children can cope with having a chronically ill/disabled brother or sister.

Begun (1989) studied the qualitative aspects of sibling relationships of sisters of developmentally disabled children. While there was no simple relationship between sibling characteristics and the type of relationships, they reported that older sisters were satisfied with their relationships with their disabled brother or sister, contradicting earlier research reporting dissatisfaction with their relationships as a result of increased caretaking responsibilities (Stoneman et al., 1987, 1988, 1989; Orsillo et al., 1993). .

Faux (1991) studied healthy, school-aged siblings' perceptions of having a

physically impaired brother or sister on the well siblings and family life and compared sibling and maternal perceptions. Protective and helping sibling activities and concerns described were similar to those noted by Menke (1987). In contrast to Stoneman et al. (1987, 1988, 1989), the majority of older sisters were not assigned nor assumed more helping and childcare responsibilities.

Gallo et al. (1991) interviewed siblings of chronically ill children to explore their perceptions of the illness, their approach to management, and the impact that the illness had on their lives and their family. Major categories revealed in the interviews were: revealing the chronic illness to others, sibling responses to the ill child, and impact on daily living. The decision to reveal or not reveal the child's chronic illness was based on their understanding that having a chronic illness places a stigma on the ill child that may negatively affect their social acceptance. The majority of siblings divided their world into a larger group, mostly of friends whom they selected to tell, and a smaller group to whom they told nothing. Most did not report any major changes in their daily lives or peer relationships. Many of them identified a variety of activities that they performed for the ill child that they would not ordinarily do if the child were not ill. Gallo et al. found that siblings exhibited compassion, tolerance, and empathy for the ill child. Although some may have ambivalent feelings about the ill child, their understanding of the effect of the potential stigma on the ill child and the sibling's desire to understand the problems associated with the illness might provide the impetus to choose to help even when the sibling would prefer not to be helpful.

These studies demonstrated that the siblings develop an increased acceptance of

human differences, a less casual attitude toward good health, positive feelings of being responsible for helping their brother or sister, and improved communication skills with family members and community professionals.

Mixed Effects

Rothery (1987) found that siblings of children with a disability struggle with the nature and extent of their sibling's disability and its implications for their own lives. However, when they are coping effectively with both their own developmental tasks and life with a disabled brother or sister, they act as playmates, role models, and teachers for their disabled sibling and contribute to the stability of the family as a whole.

Wilson, Blacher, and Baker (1989) reported that many siblings viewed their interactions with their disabled brother or sister as successful, however, the reports were not entirely positive. The siblings admitted sadness, anxiety, and anger; for a minority, these negative feelings were the most evident.

Haverman and Eiser (1994) found that siblings of children with cancer reported positive effects (ie. more empathy towards others and a greater appreciation of life) as a result of the illness, while their interpersonal relationships with others (especially parents) were more negatively affected. Better communication with parents was related to less of an impact of the illness on life generally.

Siblings of children with cystic fibrosis and asthma also reported both positive and negative affects (Derouin & Jessee, 1996). Positive outcomes included strengthening of family relationships, achieving more personal independence, and satisfaction in seeing improvement in the ill child. Negative outcomes included being jealous of the attention

paid to the ill child, reduction of family events, and worry about the illness. Similar to Menke's (1987) study, worry was reported as the most difficult thing about having a brother/sister with a chronic illness.

<u>Summary and Critique</u>

Many of the early studies reporting negative effects failed to use comparison groups, used a wide variety of methods, and collected data from sources other than the siblings themselves. There are serious limitations to relying on observations and reports of others (eg. parents and teachers). Walker (1988) found a 44% disagreement between sibling's and parent's reports of sibling coping. Menke (1987) reported that parents and siblings did not agree about the nature of the worries and concerns of siblings.

Studies since 1980 have improved design and methodology. Many researchers included both well and ill siblings, as well as parents, and used quantitative (observations, questionnaires) and qualitative (intensive interviews, participant observation) methods to obtain more valid, complete descriptions of the sibling's experiences.

Although most study findings did not appear to be affected by the type of chronic illness or disability, it should be noted that the research is very heterogeneous with respect to the severity and type of chronic illness or disability. In contrast, Derouin & Jessee (1996) reported significant illness-specific group differences. Therefore, it may be very important to distinguish different disabilities if we are to understand their effects on siblings. Most sibling research has concentrated on clearly visible disabilities such as severe mental retardation, physical and sensory impairments, and some chronic illnesses. Siblings of children with TBI, often a less visible condition, have largely been ignored.

Impact of Brain Injury on the Family

Coping with the impact of brain damage following a severe brain injury has been described as one of the most difficult tasks confronting a family (Florian, Katz, & Lavav, 1989; Lezak, 1987; Oddy, Humphrey, & Uttley, 1978; Livingston, Brooks & Bond, 1985), disrupting family relationships (Hall, Karzmark, Stevens, Englander, O'Hare, & Wright, 1994; Zarski, DePompei, & Zook, 1988), shifting social roles within the family (Blazyk, 1983; Brooks, 1991), and resulting in general adjustment problems (Lezak, 1987). Many studies indicated that the family's ability to provide support for the brain injured individual was instrumental to the length and degree of their recovery (Birmaker & Williams, 1994; Brooks,1991; Kozloff, 1987; McKinlay, Brooks, & Bond, 1981; Oddy & Humphrey, 1980). Behaviours of an individual with brain injury have been found to be part of a series of interactions that support and are supported by the family system (Lewis, & Khaw, 1982; Sargent, 1983; DePompei & Zarski, 1989; Zarski, Hall, & DePompei, 1987).

Common problems, which affect a significant number of families and their brain injured member, have been reported (Krefting, 1990; Kreutzer, Marwitz, & Kepler, 1992; Rogers & Kreutzer, 1984). The family faces financial difficulties, changed family roles, and the prolonged dependency of a person with significant personality changes, inappropriate social behaviours, and physical disabilities. Family members often report depression and feelings of being overwhelmed which persist for years following the injury (Krefting, 1990).

Family Adjustment

The burden on caregivers of an individual with brain injury depends greatly on the perception of the caregiver as well as their capacity to cope (Livingston & Brooks, 1988). Research has indicated that brain injury challenges a family's coping resources, but investigations of the role and ways of coping have focused on adult family members only (Maliak, Powell, & Torode, 1995; Moore, & Stambrook, 1994; Moore, Stambrook, & Peters, 1991). Recent studies have resulted in seemingly dissimilar findings. Frank, Haut, Smick, Haut, and Chaney, (1994) found that families of individuals with brain injury emphasized family cohesion as a means of coping. Moore, Stambrook, and Peters (1991) demonstrated that family coping and marital resources are overwhelmed by brain injury, so that coping may have only a minor role in eventual outcomes. They reported that external circumstances such as improved child care, patient care services, and increased social support, may be the overriding factors in predicting outcomes. Others reported that the most commonly reported psychosocial reactions of the family members include denial (Florian, et al, 1989; Romano, 1974), anger (Florian et al., 1989; Lezak, 1986; Stern, Sazbon, & Becker, 1988), anxiety (Livingston et al, 1985), and depression (Livingston et al, 1985; Oddy et al, 1978; Rosenbaum & Najensen, 1976).

Florian et al. (1989) reported that the process of coping with a disability, both for the individual and the family, is based on the assumption that at the acceptance stage, a balance (i.e., a stabilization of psychodynamic and psychosocial processes) between the past and the present is achieved. However, in the adjustment of brain injured individuals and their family members the usual natural adjustment process found in other physical

disabilities does not always exist (Frank et al., 1994). The deficits in mental and behavioral coping have a detrimental effect on this adjustment process. Thus, the family experiences a consistent and sometimes increasing burden over an extended period of time.

Florian et al. (1989) stressed that the family members themselves are a high risk group for emotional and social difficulties. Despite an awareness of the importance of the family in the recovery of the brain injured family member, there is little research on the impact of this disability on the family members and even less attention has been focused on the impact on siblings of brain injured survivors (Orsillo et al., 1993; Spanbock, 1992).

Johnson (1995) studied the lived experiences of a family with TBI and reported that although similar themes emerged from the parent's and sibling's interviews, the perspective and meaning of the experience differed significantly between parents and siblings. Because of age, maturity, and life experiences, siblings are a population typically limited in skills necessary to cope and adapt to the stress and pain that confronts their everyday existence dealing with a brain injured family member (Orsillo et al., 1993).

Siblings and Brain Injury

Kozloff (1987) concluded that there are few studies that have explored the relationship of the family members to the brain injured individual and the differences in their reactions. Of the 30 studies reviewed in the discussion "impact of traumatic brain injury on the family" only three mentioned the impact on the siblings. Waaland and Kreutzer (1988) also reported that the effect of a brother or sister with a brain injury on siblings has rarely been studied.

Orsillo et al's (1993) study supported their hypothesis that siblings of severely head-injured individuals experience significant psychological distress as long as five years post injury. They found that 83% of siblings reported experiencing stress, which was much greater than the 25% to 61% reported by earlier studies (Panting & Merry, 1972; Livingston et al., 1985; Rosenthal & Young, 1988), and that, depending on their age, siblings of head injured individuals may not have the emotional or verbal capabilities necessary to express the thoughts and feelings they experience in reaction to the injury. Siblings perceived themselves to be poor problem solvers and demonstrated deficits in family functioning. The severity of the brain injury was not found to be related to the sibling's level of distress. Brain injury in a family member can stretch the adaptive capacity of the family system to it's limit, compounding whatever problems existed prior to the injury.

Behavioral, social, emotional, and cognitive changes in the individual with TBI are more enduring and disabling than physical disability (Fahy, Irving, & Milloc, 1967; Klonoff, Clark & Klonoff, 1993; Lezak, 1987). Behavioral difficulties and personality

changes of the individual with a TBI were cited as primary contributors to stress in many studies (Brooks et al., 1986; Kozloff, 1987; Livingston, 1987; Livingston et al., 1985; Tarter, 1990). It can be especially difficult for siblings to deal with inappropriate social interactions of their brother or sister. They often report that their sibling's behaviour is embarrassing. Siblings' lack of understanding about how the cognitive-communicative deficits affect behaviour can interfere with their ability to develop positive interactions with their brain injured brother or sister (Blosser & DePompei, 1994).

Bragg, Klockars, and Berninger (1992) noted that siblings of brain injured adolescents reported less autonomy than did brothers and sisters of non brain injured siblings, and they had a more pessimistic view of the handling of autonomy within the parent-adolescent relationship in their families. Furthermore, Trahd (1986) reported that a potentially important characteristic of the sibling relationship that could impact on how well siblings cope with brain injury in a brother or sister is the longevity of the relationship. This longevity may result in a long-term burden on the siblings to support the brain injured individual. Oddy et al (1978) found that one of the most potent stresses experienced by family members comes from a concern for the brain injured individual's future. It is quite possible that this concern may be especially relevant to siblings of head injured individuals.

Gill (1998), in a qualitive study with siblings age 14 to 30 years of age of older adolescents with TBI, found that the main theme reported by siblings was that their lives had changed forever following their brother's or sister's brain injury. The siblings reported mixed emotions in reaction to the changes.

This review of literature found only four research studies which included siblings of children with brain injury (refer to Table 2). Two of these focused on siblings of children with TBI and used quantitative methodology, while two used qualitative methodologies; one a phenomenological nursing study examined all members of one family and the other described the experiences of siblings of adolescents with TBI. Kay and Cavallo (1994) reported that the majority of family assessment instruments are inadequately sensitive to particular issues specific to brain injury.

Summary of the Literature Review

The long-term impact of brain injury on the entire family and the importance of the family's positive adjustment to enhance their ability to provide support to the head injured member has been recognized. The importance of the sibling relationship to the overall development of children has been well documented. Studies examining siblings of children with other disabilities suggests potential areas of similarity to those with brain injury. However, childhood brain injury is significantly different than other childhood chronic illness/disability. Most of the information on siblings of brain injury has been derived from quantitative studies of families of adults with brain injuries. Quantitative family assessment instruments are inadequately sensitive to particular issues specific to brain injury. Thus, qualitative methods of examining the impact of a child's brain injury on their siblings would provide a better understanding from which to consider the needs and perspectives of siblings, who may view themselves quite differently than other family members do. To date, there is little research examining the specific experiences and

perceptions of siblings living with a brother or sister with a brain injury.

Nurse are in a unique position to assist in the successful adaptation of all members of the family of children with a brain injury. A better understanding of the impact on siblings of living with a brother or sister with a brain injury will enable nurses to anticipate potential problems for siblings, and assist them to achieve a more positive and supportive role in the recovery of the child with a brain injury, as well as their own development, and enhance family well-being.

Table 1

Summary of Selected Studies of Siblings of Chronically Ill/Disabled Children

AUTHOR	SAMPLE	DESIGN & METHOD	FINDINGS
Negative Effects			
Ferrari (1987)	N=60, 30 siblings of children with juvenile diabetes - 30 matched siblings of well children; 7.6-12.5 years of age	Quantitative, Correlational Piers-Harris Children's Self - concept Scale	Siblings of children with JD had lower self-concept scores with regard to intellectual & school status, happiness & life satisfaction.
McHale & Gamble (1987, 1989)	N=62, 31 siblings of children with mental retardation - 31 matched siblings of well children; 8-14 years of age.	Quantitative, Descriptive Structured telephone interviews of siblings	Older sisters of children with mental retardation showed poorer adjustment in depression, anxiety, self -esteem, & conduct problems. Older brothers were more anxious, lower self-competence in social acceptance & conduct.
Stoneman et al (1987, 1988, 1989)	N=64, 16 pairs of siblings containing a mentally retarded child 16 matched pairs of siblings both normal older siblings 6-12 years of age, younger siblings 4-8 years of age	Quantitative, Correlational Sibling-structured interviews, observations of sibling interaction. Mothers - Same structured interview questions, Vineland Social Maturity Scale, Verbal Language Development Scale	Multiple care-taking responsibilities by older sisters were associated with sibling conflict & increased social isolation.
Breslau & Prabucki (1987)	N=192 siblings & parents of children with severe physical disabilities 284 siblings & parents of well children. 6- 18 years of age at initial assessment & 11- 23 years of age at 5 year follow-up	Quantitative Longitudinal study Structured interviews; Siblings-diagnostic Interview Schedule for Children. Mothers-Psychiatric Screening inventory	Siblings of disabled children experienced higher levels of aggression, increased depression & social isolation. Younger siblings had the largest increase in depression & social isolation.
Tritt & Esses (1988)	N= 27 siblings,	Quantitative,	Siblings of children with

AUTHOR	SAMPLE	DESIGN & METHOD	FINDINGS
	11 of children with diabetes, 10 juvenile rheumatoid arthritis, 6 Gl disorders 27 siblings of well children	Correlational Questionnaires- parents & siblings. Interviews-siblings.	illness had greater incidence of withdrawal & shyness than siblings of well children. Self-concept did not differ .

Positive Effects

AUTHOR	SAMPLE	DESIGN & METHOD	FINDINGS
McHale,Sloan, Simeonsson (1986)	N=90, 30 siblings of children with autism, 30 mental retardation, 30 siblings of well children 6-15 years of age	Quantitative, Correlational Siblings - 26 question open-ended interview, Sibling Problems Questionnaire; Parents - Sibling Behavior Rating Scale	Specific problem areas (e.g., perceptions of parental favoritism, coping ability, concerns of handicapped child's future) related to quality of sibling relationships. Sibling relationships rated positively by both siblings & mothers
Menke (1987)	N=72 siblings of children with cancer, cystic fibrosis, myelomeningocele, burns 7-12 years of age	Quantitative, Descriptive Sibling interviews/ Parent interviews	Majority of siblings worried about ill child, siblings & parents reported positive sibling changes since initial diagnosis of ill child. Discrepancy between sibling & parent report of nature of worries.
Walker (1988)	N= 26 siblings of children with cancer 7-12 years of age	Qualitative, Grounded theory Siblings - open-ended interviews including puppet play, drawings, cartoon story-telling, sentence completion & direct questions.	Coping efforts were cognitive (intrapsychic, inter-personal, intellectual) & behavioral (self-focusing, distraction, exclusion). 44% disagreement between parents & siblings' reports of coping efforts.
Begun (1989)	N=46 sisters of children with developmental disabilities & normal siblings 12- 69 years of age	Quantitative, Correlational Questionnaires to measure Qualitative aspects of	Demonstrated no simple relationship between birth order, age spacing, gender, & living arrangements &

AUTHOR	SAMPLE	DESIGN & METHOD	FINDINGS
		sibling relationships.	their affect on type of relationship. Older sisters were satisfied with their relationships with disabled children.
	N=67, 22 siblings of children with crainiofacial anomalies, 20 cardiac anomalies/ 25 siblings of well children 7-12 years of age	Quantitative, Descriptive Sibling interviews, Maternal interviews Sibling Inventory of Behavior (S/B) Children's Report of Parental Behavior (CRPBI)	No significant difference among groups on CRPBI or S/B. Majority of siblings & mothers described good sibling relationships & minimal negative impact of illness on well sibling.
Faux (1991)	N=28 siblings of children with diabetes, cystic fibrosis, juvenile rheumatoid arthritis, chronic renal failure 6- 16 years of age	Quantitative, Descriptive Sibling interviews, Parental interviews, Questionnaire Child Behavior Checklist (CBCL); tool & interviews conducted twice, 12 months apart	42% of siblings would not disclose sibling's illness to others; CBCL scores within normative range, Parents reported that as a group, siblings did not experience a significantly higher incidence of behavior & social problems.

Mixed Effects

AUTHOR	SAMPLE	DESIGN & METHOD	FINDINGS
Wilson, Blacher, & Baker (1989)	N=24 siblings of children with severe handicaps 9-13 years of age	Quantitative, Descriptive Siblings - semi-structured interviews, Sibling Statement Scale	Siblings reported both positive & negative effects. Siblings reported sadness, anxiety, & anger & for a minority negative feelings were most evident.
Haverman & Eiser (1994)	N=21 siblings of children with cancer 4- 1 8 years of age	Quantitative, Descriptive Siblings Semi-structured interviews, Sibling Perception Questionnaire. General Impact Scale	Siblings reported positive effects (increased empathy - appreciation for life). Interpersonal relationships with others negatively affected, especially parents. Improved communication related to less of impact of

AUTHOR	SAMPLE	DESIGN & METHOD	FINDINGS
			illness in general.
Drouin & Jessee (1996)	N= 15 siblings of children with cystic fibrosis & asthma 8-17 years of age	Quantitative, Exploratory, Descriptive Structured phone interviews Siblings - Klein's Sibling Questionnaire, Piers-Harris self-concept Scale Parents - Questionnaire on family functioning.	Siblings affected both positively & negatively. Definite illness-specific group differences. Worry was the most difficult thing reported.

Table 2

Studies of Siblings of Children with Brain Injury

AUTHORS	SAMPLE	DESIGN & METHOD	FINDINGS
Bragg et al. (1992)	N=60, 30 families with an adolescent with a mild to moderate TBl, 30 families with well adolescents. TBI adolescents 14-18 years of age, siblings 11-22 years of age	Quantitative, Correlational Siblings - Family Assessment Device (FAD), Family Autonomy Scale (FAS) Parents -Maladaptive Behavior Domain	Parent's rated family's level of functioning higher than did siblings. Siblings & TBI adolescents reported lower degree of autonomy than control group.
Orsillo et al (1993)	N=13 siblings of children with a brain injury	Quantitative, Descriptive Questionnaires Siblings - McMaster Family Assessment Device (FAD), Problem Solving Inventory (PSI), Dysfunctional Attitude Scale (DAS), Rational Behavior Inventory (RB1), Attributional Style Questionnaire (ASQ), Revised Ways of Coping Checklist), Brief Symptom	83% of siblings experienced significant psychological distress as long as 5 years post-injury. Siblings had a negative self-appraisal of their effectiveness in problem solving. Siblings displayed emotional coping strategies of wishful thinking, avoidance, & self-blame more often than more problem-focused strategies.

AUTHORS	SAMPLE	DESIGN & METHOD	FINDINGS
		Inventory (BSI).	
Johnson (1995)	N=One family with TBI	Qualitative, Phenomenology	Parents and sibling interviews - emerging themes: 1. helplessness and the need to hope; 2. need to be informed and involved; 3. impact of intubation/ extubation. Victims' interviews- emerging themes: 1. going home; 2. concern for others; 3. piecing it together.
Gill (1998)	N= 8 siblings of brothers and sisters with brain injury Age 14-30	Qualitative, exploratory Semi-structured interviews	Emerging themes- Forever different; change in sibling, mixed emotions, different life rhythm, change in self.

CHAPTER III

METHOD

The method best suited to meet the purpose of this study is Glaser and Strauss'
(1967) "grounded theory " methodology. When little is known about a phenomenon and
the purpose of the researcher is to gain insight into the phenomena from the participant's
perspective, the choice of the research method should be a qualitative one (Brink &
Wood, 1993; Leininger, 1985; Morse & Field, 1995). In research with children the child-
subject's and the adult researcher's frame of reference differ widely because of
differences in maturation and experience. Quantitative measures reflect the adult's a
priori perception of what they perceive to be the child's perceptions, attitudes, and
knowledge about a topic (Faux, Walsh & Detrick, 1988). Using quantitive methods such
as closed-ended questionnaires with children assumes that the researcher is aware of the
child's frame of reference and can identify exclusive and exhaustive categories of
response. Qualitative methodology provides a framework within which children can
express their own understandings in their own terms (Bernheimer, 1986). In this study,
the purpose was to obtain information and develop an understanding of the impact of a
child's brain injury on their siblings from the sibling's perspective. Since little is known
about the phenomenon of living with a brother or sister with a brain injury, it is
appropriate to use a qualitative method.

In this chapter, the methodology of this research study will be described. The
qualitative approach employed in this research study will be discussed, as will the

research design, issues of rigor, and ethical considerations.

Qualitative Method: Grounded Theory

Grounded theory is a method of qualitative research that is used for preliminary exploratory and descriptive studies in an area where little research has been done (Glaser & Strauss, 1967). This method was developed from symbolic interactionism, a school of thought that views human behavior as being part of a social process (Glaser & Strauss, 1967). Symbolic interactionists posit that, rather than just reacting, individuals create order in their world by engaging in processes of negotiations and renegotionations on the basis of various symbols which have meaning and value for them. Grounded theory involves the discovery, development, and verification of data which has been systematically collected and analysed. In grounded theory, the researcher generates theoretical constructs or basic social processes rather than verifyies existing theory (Strauss, & Corbin, 1990).

This method is both an inductive and deductive approach to theory construction (Morse & Field, 1995). With this approach, data analysis occurs simultaneously with data collection. Concepts are grounded in the data and hypotheses are continuously tested against new data. Ongoing data collection is guided by theory generation.

The Sample

Sample size in qualitative research may refer to numbers of interviews as well as numbers of participants (Sandelowski, 1995). In qualitative research the adequacy of the sample refers to the "sufficiency and quality of the data" (Morse, 1989, p.122). The

number of participants or interviews to include in the study using theoretical sampling is impossible to predict, however Chenitz & Swanson (1986) state that 20 to 50 interviews will "elicit major and repetitive themes" (p.70). In this study 12 participants were each interviewed twice for a total of 24 interviews.

Purposive Sample

In a qualitative research study, it is important to interview key informants who have knowledge of/or experience with the phenomena being studied, are willing and have the time to participate, and can express their experiences in a reflective manner. Participants who meet these criteria provide a rich source of data which will enable the researcher to fully describe the phenomenon being studied (Morse & Field, 1995). Informants participating in this research study possessed all of these qualities. However, younger participants, due to their evolving cognitive development, occasionally had difficulty articulating their feelings.

Recruitment of the Sample

Siblings of children with a brain injury were recruited by a variety of means. The co-ordinator of a pediatric brain injury rehabilitation program at a large rehabilitation hospital acted as an intermediary to access families of children who had been former patients of the program. A letter containing information about the study (Appendix A), a letter of endorsement from the co-ordinator, and a form with a stamped pre-addressed envelope to return to the researcher indicating interest in participating in the study, was included with a regular information letter from the pediatric program to these families. Due to the complexity of restricting this mail out to families with a child with TBI, as was

originally determined, the information was received by families with a child with an ABI as well as those with a TBI. Five potential participants, four of whom had brothers with an ABI replied to this recruitment effort. As a second means of recruitment, the same information was given to parents attending a parent support group sponsored by another organization. No potential participants were identified from this method. Although the size of the sample was not predetermined, an adequate sample was thought to require 10 to 15 participants. Thus, a second mail out from the pediatric brain injury coordinator was planned. However, due to a threatened postal strike the coordinator telephoned families, explained the study and gave them the researcher's name and telephone number to contact if they were interested. Nine potential informants were found from this contact. Parents who were willing to allow their children to participate in the study contacted the researcher by returning the form enclosed in the letter or by calling the researcher at the number provided. Parents who returned the form by mail were contacted by the researcher by telephone to arrange an initial interview.

The initial inclusion criteria for this study included siblings of children who: had experienced a TBI at least one year ago, were six to eighteen years of age, lived in or within a two hour drive of Edmonton, and understood and spoke English. Justification of the inclusion criteria was as follows. Coping with a brain injury has been described as one of the most difficult tasks confronting a family (Florian et al., 1989). Approximately one to two years following a brain injury was thought to be the minimum time required for a family to have achieved some adjustment and to be able to reflect on the impact of the child's brain injury on their lives (Krefting, 1990). Deatrick and Faux (1989) state that by

age six a child has the cognitive, linguistic, social, and emotional maturity to be a valid and reliable informant. The researcher accepted more than one sibling from each family for two reasons: each individual's perspective is unique based on their relationship to the affected child and their own perceptions of the situation (Dunn & McGuire, 1994), and the target population within the designated geographical area was relatively small. Following the poor response to the first two recruitment attempts, it was determined that perhaps the inclusion criteria needed to be relaxed regarding sibling age, and cause of brain injury in order to obtain an adequate sample. Therefore the criteria were amended, with the approval of the ethics committees and the researcher's thesis committee, to include siblings, who were eighteen or younger at the time of their sibling's brain injury, who were at least six years of age at the time of the first interview and to include both TBI and ABI. It is difficult to determine whether the amended criteria or the personal contact by a health care professional with whom the families had developed a good rapport was responsible for the improved response to the third recruitment effort. However, I suspect that the personal contact was the reason, as many of the families spoke highly of this individual and the support that he had provided their families.

Twelve informants were chosen from those that indicated a willingness for their children to participate in the study. One potential informant was not included in the study because of the difficulty of arranging an initial interview due to his very busy schedule. The second potential informant was not chosen when the researcher became aware of the renewed distress the interview with her child was going to cause this parent. Therefore, after further consultation with these parents, the sibling was thanked for his interest and

not included in the sample.

Sample Size

Qualitative research studies depend on the quality of the data obtained rather than the number of research participants. Data collection continues until saturation of the emerging categories is obtained (Morse, 1994). Twelve siblings were informants in this study.

Characteristics of the Sample

Purposeful selection was employed to obtain as equal representation of siblings of children with ABI and TBI as possible. Five informants had a brother with ABI and seven informants had a brother with TBI. Families described their perception of the child's brain injury as mild (2), moderate (4) and severe (6). Demographic information (Appendix D) was collected from each family to assist with theoretical sampling and description of the participant group and their families. A parent completed the questionnaire for siblings under sixteen years of age. All other informants were able to complete the questionnaire themselves. There was diversity in all demographic indicators with the exception of the injured child's gender: all were male.

Five informants were female and seven were male. Ages ranged from seven to twenty-one years at the time of the interview; four were 13 years of age or younger, four were between 14 and 17 years of age, and four were 18 or older. The time since the injury ranged from one and a half to ten years, with a mean of five years. Birth order in relation to the brother with a brain injury was evenly split, six older and six younger.

Family income ranged from $20,000- $40,999 to $100,000 and above, with a

mean of $50,000- $79,000. Eight families lived in an urban community and four families lived in a rural area. All but one sibling had two parents living with them, and family size ranged from two to five children, with a mean of two children.

<div align="center">Data Collection</div>

The initial telephone contact was used to describe the nature of the research in general terms, to answer any questions, and to arrange a time for the first interview for respondents who met the study criteria. Interviews were conducted by the researcher at a time and place convenient for both participant and researcher. Eleven informants chose to be interviewed in their home in various locations of their choosing where they felt most comfortable. Interestingly only two informants chose their bedroom with most prefering the kitchen, family or living room in that order. The twelveth informant chose to be interviewed in a conference room at the university to better accommodate his busy schedule. Prior to beginning the first interview, the information sheet containing an explanation of the study was reviewed with both the parent (s) and the sibling participant. The informed consent (Appendix B) was obtained from the parents of informants less than nineteen years of age, and an assent form (Appendix C) was signed by siblings seven years of age or older. Informants over eighteen years of age signed their own consent.

Data for this study was collected primarily through the use of audiotaped unstructured interviews that were then transcribed verbatim. Additional data consisted of participants drawings, and researcher field notes. When the researcher wants to understand a child's feelings, concepts, and frame of reference, credibility of data is increased with the use of open-ended questions (Faux et al., 1988). Initial open-ended

questions such as "Tell me what happens to a person when they have a brain injury ?" to determine the siblings understanding of what has happened to their brother and "Tell me what it has been like for you since X's brain injury" were asked at the beginning of the initial interview. Additional nondirective probes (Appendix E) were used if participants needed help to articulate their experiences. Flexibility of questions to accommodate for the age and developmental level of each participant was maintained. The second interview became more structured to further explore categories identified from analysis of data from the first interviews.

The researcher took steps to create a relaxed, safe atmosphere and to develop a rapport with the participant prior to beginning the interview. The participant was assured at the beginning and throughout the interview that there are no right or wrong answers and that not always having an answer is all right (Rich, 1968). Having a child draw pictures of himself/herself or his/her family has been used extensively in nursing studies of school age children to establish rapport and decrease the child's anxiety (Aamodt, 1972; Beck, 1996; Carson, 1986; Faux et al., 1988). Drawing while talking about her experiences was of great benefit for one informant. The entire first interview was conducted while she drew pictures of her family and of she and her brother playing. This made for a more lenghty interview than others but elicited a large amout of relevant data. For the second interview her mother suggested that she wait until the interview was finished before drawing her picture, with the idea that it would decrease the length of the interview. However, this proved to be a mistake, as the child appeared to be self conscious while the interview was being recorded. This interview elicited very little data

until the recorder was turned off and she began to draw another picture. Children's

drawings are a language, a way of symbolically communicating their thoughts, feelings

and experiences (DiLeo, 1983; Klepsch & Logie, 1982), and thus, asking informants to

explain their drawings provided additional information about their thoughts, feelings and

experiences of living with a brother who has a brain injury. Observational, theoretical,

and methodological field notes were made. Observational field notes documented the

nonverbal content and the context of the interviews, and the impressions of the researcher

(Morse & Field, 1995). Theoretical notes contained thoughts and beginning

interpretations as the researcher reflected on the early analysis of data. Methodological

field notes contained information about the research process.

Initial participants who met the study criteria were interviewed to uncover

phenomenal variations. In theoretical sampling the researcher simultaneously collects,

codes, and analyzes the data, and selects the next participants according to the needs

identified from the emerging data. However, sampling in this study was more purposive

than theoretical due to a preponderance of informants who had brothers with ABI from

the initial recruitment. Therefore, most of the second group of respondents were included

to provide an adequate balanced sample. Two interviews were conducted with each

participant. The length of each interview depended on the individual participant.

Interviews for school-age informants (6 to 10 years of age) ranged from 25 to 45

minutes.Older informants' interviews lasted from 30 to 70 minutes.

Data Analysis

In grounded theory, data analysis occurs simultaneously with data collection with

a responsive interaction between the two. This is a circular method where the researcher focuses on exploring areas revealed by the ongoing data analysis. The purposes of data analysis are to code the data so that categories may be recognized, analyzed and described and to develop a data filing system that is flexible with procedures for retrieving data (Field & Morse, 1985).

Data analysis began following the first interview. Twenty-two interviews with informants were completed by the researcher over a six month time period. The interviews were audio taped and each tape was transcribed verbatim by a typist.The transcriptions were then carefully reviewed with the tape recording to ensure accuracy. A systematic method of organizing all of the data obtained was implemented in the form of field notes, memos, and a journal. Field notes were taped immediately following the interview and included a description of any interruptions during the interview, information about the setting, and a description of the participant. Memos which included a reflection of the experience from the researcher's perspective assisted in identifying gaps in the ongoing analysis and new potential related directions for the emerging theory. A journal used during analysis of the data kept track of the definition of terms, decisions about the analysis and the line of questioning, and the dates that events occured. The NUD*ist 4.0 computer software program was used to organize all of the data which enabled the researcher to identify and sort data efficiently and classify data into multiple categories. This program also enhanced the researchers ability to maintain a clear audit trail.

Analysis of interview data began with open coding in which the data was

analyzed for recurring words, phrases, themes or concepts related to the responses of the participants. Individual incidents were coded as a concept or abstraction of the data. Similar concepts were grouped together as coding evolved. With the grouping of similar concepts each category was given a conceptual name reflective of the concepts grouped within it. Interviews became more focused and questions became more specific as categories began to emerge and ideas about how the phenomena may be related to each other developed. This allowed the researcher to validate and clarify information as the data collection and analysis proceeded

When all of the interviews were completed connections between categories were made utilizing the process of axial coding (Strauss & Corbin, 1990). Through axial coding the properties of each category were identified, which allowed for the identification of its antecedents, consequences, conditions and the context surrounding each category.

A core category, "changing lives," was identified through the process of selective coding. In selective coding, all of the substantive codes are categorized, recategorized and condensed, elevating the process to a higher level of abstraction. At this step coding is limited to those categories that relate to the core variable in "sufficiently significant ways to be used in a parsimonious theory" (Glaser, 1978, p. 75). Diagramming of possible relationships between the core category and other categories resulted in a conceptual diagram of the beginning theory. A story line that captured the categories and processes involved in the experience of living with a brother with a brain injury was developed. At this stage, it became clear that the stress, appraisal and coping framework of Lazarus and

Folkman (1984) fit with the study findings.

A second literature review was completed after identification of the process, core category and sub-categories. This secondary literature covered areas of children's coping and adaptation, loss theory and the concept of hope. The knowledge obtained from the literature review and the process identified in the data resulted in the development of a beginning theory which describes the process siblings go through as they learn to live with a brother or sister following his/her brain injury.

The process of data collection and analysis is a cyclical process as data analysis occurred throughout the data collection process. The data analysis was enhanced at all stages through the use of analytic and process memos by which the researcher recorded ideas, insights, thoughts and impressions about the emerging theory (Morse & Field, 1995). Analytic memos documented the researcher's ongoing effort to "theorize" about the data. Process memos described the researcher's observations about the participants behavior, about the researcher's own interaction with participants, and decisions made regarding the conduct of the study. The sorting of these memos provided another opportunity to group concepts (Stern, Allen, & Moxley, 1984).

Rigor in Qualitative Research

Rigor is an issue of serious concern to the qualitative researcher. Grounded theory methodology generates theory rather than testing it. Therefore, criteria for determining reliability and validity differs significantly from those in quantitative research (Krefting, 1991; Morse & Field, 1995; Sandelowski, 1986). The purpose of this study was to

describe and gain an understanding of the impact of a child's brain injury on his/her siblings from the emic perspective of the siblings using a qualitative methodology. Thus, it was appropriate to use qualitative criteria to evaluate the methodology of the study.

Rigor in qualitative research is related to the trustworthiness of the research (Krefting, 1991). Sandelowski (1993) wrote that trustworthiness "becomes a matter of persuasion whereby the scientist is viewed as having made those practices visible and, therefore auditable" (p. 2). Trustworthiness can be determined using four criteria: credibility, fittingness, auditability, and confirmability (Sandelowski, 1986). These criteria were used to assess the reliability and validity of this study.

Credibility

Credibility depends on the researcher's abilities to faithfully describe and interpret the participant's experiences (Sandelowski, 1986). As with all qualitative research the data was obtained directly from the participants, therefore the data is grounded in the experiences as perceived by the participants, rather than data obtained using an instrument or scale defined and developed from the researcher's perspective.

Several strtaegies were used in this study to enhance credibility. Two interviews were conducted with all informants to allow rapport to develop and allow the researcher an opportunity to clarify earlier information and add depth to previously collected data. The researcher contributed to this study by her personal experiences as a mother of a child with TBI and a special interest in sibling's experiences as a result of observations as a pediatric nurse. This contributed to the researcher's sensitivity to and understanding of these siblings, thus allowing more accuracy and depth in interpretation of the data.

Because qualitative methods require personal interaction, bias was unavoidable. Hall and Stevens (1991) recommend that the elimination of bias in qualitative research is impossible and inappropriate. However, various means to minimize bias were employed by the researcher. These included frequent reporting to her thesis supervisor, maintaining a journal, and having her supervisor read her field notes, interviews, and final report. The research journal was used to record subjective impressions and initial reactions which served to assist in recognition of assumptions and bias.

Fittingness

The criterion of fittingness has been achieved when the findings fit into the contexts other than the study situation, the audience and others see the findings as relevant to their own experiences, and when the findings fit the data from which they were derived (Sandelowski, 1986). A sibling who met the study criteria, but had chosen not to participate due to a personal relationship with the researcher, was asked to review the findings to determine the relevancy to her own experience with the phenomena. As well, the findings were shared with several health care professionals who work with families of children with brain injury.

Auditability

Sandelowski (1986) stated that auditability is the criterion for determining reliability. Auditability is evidenced when another researcher can follow the progression of events or "decision trail" (also referred to as the audit trail) of the researcher and reach similar conclusions. Essential elements of an audit trail of researcher generated data include contextual memos (fieldnotes), memos explaining methodological choices,

memos about the procedures of data analysis, and memos related to the role of the researcher as a research tool (Rodgers & Cowles, 1993). Several strategies to ensure auditability included: (a) detailed documentation of the procedures of data collection and analysis in field notes, memos, and a research journal, (b) regular meetings with the thesis supervisor to discuss progress of the study and, (c) preservation of the interview tapes and transcriptions so findings may be verified and confirmed by other researchers in the future if further consent is obtained.

Confirmability

Confirmability of this research study will be attained if credibility, auditability, and fittingness have been established. Confirmability of this study will be determined when the findings of this study are reported and others find them useful.

Ethical Considerations

Ethical approval was obtained from the Faculty of Nursing Ethics Review Committee, University of Alberta and The Ethics Review Committee of the Glenrose Rehabilitation Hospital, Edmonton, Alberta prior to beginning this study. Permission to speak to a parent support group was obtained. The measures that ensured that consent by parents and the participants assent was informed, and measures to protect participant's anonymity and confidentiality will be presented.

Written assent was required from participants between the ages of seven and eighteen years of age (Akers & Bell, 1994; Broome & Stieglitz, 1992; Gidding, Camp, Flanagan, Kowalski, Lingi, Silverman & Langman, 1993; Koren, 1993; Lee, 1991;

Weithorn & Scherer, 1994).

During the initial telephone contact by the researcher, parents and potential sibling participants were provided an opportunity to ask questions. Verbal consent from the parents and verbal assent from the sibling was obtained at that time, and a time and place for the first interview was arranged. Only one sibling indicated reluctance to participate in the study, even though verbal parental consent was obtained. Therefore, the sibling was not enrolled in the study. At the first interview the information sheet about the study was reviewed with one or both parents and the sibling participant. Two copies of written consent by the parents, and written assent by the participant, and two copies of the information sheet signed by the parents was obtained; one copy of each was given to the parents, and the second copy was filed in a locked cabinet to which only the researcher had access. The participants were assured that participation in the study was voluntary and that they could withdraw from the study at any time by simply informing the researcher or her thesis supervisor. The telephone numbers of the researcher and thesis supervisor were provided in the event of questions or concerns that might arise during the course of the study.

Measures to protect confidentiality of individual information as well as participant anonymity were ensured by storage of all data (audio tapes, transcripts, and consent forms) in a locked cabinet to which only the researcher had access. Consent forms and demographic information were stored separately from the data. Transcripts and consent forms will be destroyed seven years after completion of the study. Appropriate ethical clearance will be obtained prior to using any material for secondary analysis.

The participants' anonymity was protected by the following steps. Transcripts were identified by code numbers, and all names were changed. The list of names and code numbers have been stored in a separate locked cabinet from the raw data. Portions of the participants' conversations have been used in the final research report. However, participants and their brothers have been given pseudonyms. Due to the relatively small target population subject numbers have not been used when providing direct quotes and a detailed sample profile was not provided for the same reason. A summary of the findings will be sent to all parents and participants who requested a copy. Provision for requesting a summary was included as part of the consent form.

CHAPTER IV

FINDINGS

The purpose of this research was to describe and gain an understanding of the impact of a child's brain injury on his/her siblings from the emic perspective of the siblings. The results of the data analysis using the grounded theory approach (Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin, 1990) are presented in this chapter. In human experience there is usually a core category that explains both the meaning of the data (Glaser, 1978), occurs frequently, and links the variations of data. The basic social process (BSP) described by Glaser (1978) and Strauss and Corbin (1990) is a type of core category as it explains the variation in behavior present over time in the data. The BSP that emerged in this study is Changing Lives. The Changing Lives of the siblings involved three main subprocesses: a) realizing life is different, b) adjusting to the changes, and c) getting on with life.

Grounded theory may be viewed as a transactional system "a complex web of interrelated conditions, action/interaction, and consequences that pertain to a given phenomenon" (Strauss & Corbin, 1990, p. 161). Thus, antecedent conditions to the core category Changing Lives will be presented, followed by the action/interaction strategies used to manage the phenomenon. Next, the consequences of the action/interaction strategies will be presented. The process of Changing Lives occurs within the context of the sibling's family, the sibling's developmental stage, and the sibling relationship prior to the injury. These contextual conditions and any intervening conditions that influence

the strategies employed by each informant will be presented as they relate to each step of the transactional system. Additional notations regarding context and pertinent observations made during the interviews of each informant are presented.

Statements made by the informants were taken verbatim from the data to substantiate the findings. All of the children in these families who had sustained a brain injury were boys: therefore, all references to the injured siblings are to brothers. All names of informants and their brothers have been changed to protect their anonymity. Each quotation from an informant is followed by a number to indicate whether the quotation originated from the first or second interview. Because the informants come from a small population of families, subject numbers have been omitted to further protect anonymity.

Changing Lives: An Overview of the Process

The main theme emerging from the data was a process of changing lives as siblings related their experiences of living with a brother who has a brain injury. Siblings begin to realize that their lives are different as they experience disruptions to their normal routines. Daily routines are disrupted immediately following the injury, during their brother's long hospitalization and when he comes home. Normal routines are disrupted by the arrival of unexpected company immediately after the injury. They experience changes as they become more responsible for additional tasks and decide to become more responsible individuals. They become aware that their brother's personality has changed, that he has physical and cognitive changes and often exhibits frustrating and inappropriate behaviour. These changes necessitate becoming re-acquainted with their "new" brother.

At the same time they experience changes to their roles within the family. As siblings become re-acquainted with their brother and assume new roles their relationships with their brother and other family members change as well. Over time some siblings develop closer relationships while others find relationships become more strained. Closer relationships develop as they become friends, make an effort to include their brother in activities, make more time for their family and family communication improves. Relationships become more strained as siblings find they have to be more careful with their brother, experience increased fighting and choose to go their own way . Conflicts with parents and being disappointed by friends also cause strained relationships.

These changes in sibling's lives influence the strategies they employ to adjust, strategies that often change over time. Initial distancing strategies allow siblings time to absorb the changes. However, if distancing becomes a more permanent strategy it may lead to avoiding dealing with the situation. Seeking support by talking to someone about how they feel about the changes, sharing their experiences with others, and turning to God are strategies siblings find helpful in adjusting to their changing lives. Some choose to make an extra effort to help their brother, assist him in his recovery, help him fit in with friends and befriend others with disabilities. This altruistic helping provides positive strategies for siblings to adjust to their changing lives. Emoting strategies of crying or getting angry are other strategies siblings use.

The realization that their lives are changed following their brother's brain injury and the strategies they employ to adjust to these changes influences the final phase of getting on with their lives. Most siblings are able to put the changes in perspective and

acknowledge that there are positive as well as negative changes to their lives. Others reluctantly accept the changes as they get on with their lives living with a brother who has a brain injury.

An Illustrative Case

David, a university student, lives with his parents and two brothers. His older brother Brad was involved in a motor vehicle accident sustaining a severe brain injury. Brad was admitted to the Intensive Care Unit of a large tertiary hospital. Information about Brad's condition was discussed with David's parents, and David and his younger siblings were never included in these conversations. David learned about Brad's progress from their parents and sometimes from listening in on conversations between his parents and various health care professionals. David recalled that the information and outlook for Brad's recovery, presented to his parents by all of the doctors and nurses, was very pessimistic and that created as much uncertainty as not having enough information. After the accident David had less time for his normal activities and friends as he willingly assumed the role of older brother and took on additional responsibilities around the house; preparing meals, sharing Brad's usual chores, and looking after his younger brother. His parent's time was occupied with Brad, and David had much less time with his parents than usual, especially his mother, who was at the hospital all day. David's parents made an effort to make time for him and his siblings, but they could not maintain their normal involvement in their sons' activities. His mother would report on Brad's progress each evening when she came home. As well as frequent visits to the hospital David kept in touch with his brother by phone when Brad was well enough to receive

phone calls. David was upset when it became evident that Brad was no longer the same person he had been prior to the accident. David's friends and teachers were supportive. However, David did not discuss his feelings with them as he didn't think that anyone outside his immediate family could possibly understand what he was going through. He shared some concerns and frustrations with his parents and younger brother but kept most of his feelings to himself. When Brad came home David assumed the role of coach helping him in his recovery. He attempted to provide guidance with inappropriate behaviour, when Brad had difficulties with relationships and fitting in, and helping Brad pace himself when he became tired. The family worked together to find solutions to help Brad recover and to adjust to this "new" person in their family. David's mother obtained literature to help them understand the effects of Brad's brain injury. David was especially upset when Brad's friends gradually drifted away. He made an effort to include Brad in his activities to make up for his loss of friends. In the process he discovered that his brother had developed a more outgoing personality, and they became better friends than before Brad's accident. While David continues to be protective of Brad and acts as his coach, he finds that Brad's behaviour can still be embarrassing and frustrating. David becomes upset when he talks about his brother's accident and how it has affected his life. His brother's brain injury changed his life forever, but he has accepted these changes and has been able to put them into perspective. He realizes that in many ways he and his family have benefited from this experience. They are closer as a family, making more time for each other, and not taking each other for granted. David has a greater appreciation for life and has developed a better understanding of others with disabilities.
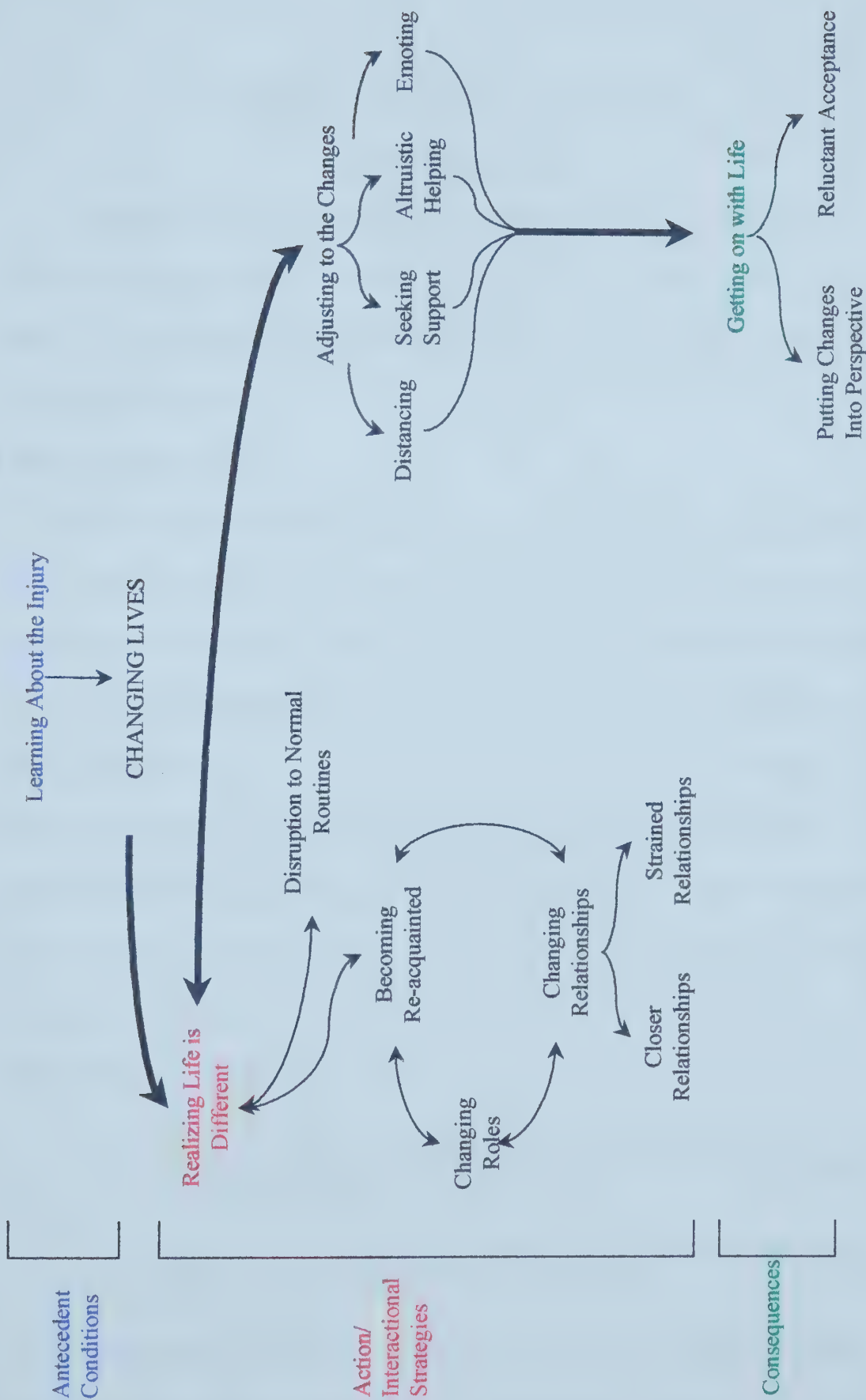
Figure 1: The Process of Changing Lives

Changing Lives: A Basic Social Process

<u>Antecedent Condition</u>

Antecedent conditions are defined as "events or incidents that lead to the occurrence or development of a phenomena" (Strauss & Corbin, 1990, p.100). In these findings, the experiences of learning about the injury led to the occurrence of the core category of Changing Lives.

Learning about the Injury

The informants described learning about their brother/sister's injury as frightening and confusing. Informants felt that they were kept in the dark regarding their brother's brain injury. Most informants reported that they were given no information about their brother's condition by doctors or nurses and only received partial information from their parents. Informants discussed how they managed to piece together information by themselves. As well as not being included in discussions about their brother, they reported feeling totally ignored by health professionals during their visits to the hospital. Informants became angry and refused to accept what they perceived to be only negative or "worse-case scenario" information from doctors. They reported that this pessimistic outlook created more anxiety and uncertainty.

> I didn't know why he was there [in the hospital]… No one told me because, I guess they didn't want to scare me….I wouldn't have been so scared [if they had told me]. (02)

> The part that I remember most clearly is he [the doctor] said, 'In the next 24 hours …..can live or die.' (01)

And they said that he had some spinal injury…and they were going to see the CAT scans and later when we came up he had some swelling of the brain…. I was scared,

I didn't know what was going to happen to him. (01)

<u>Being Kept in the Dark</u>

Only two informants recalled being included with their parents in explanations by health care professionals about their brother's condition. Other informants reported receiving only partial or no information about what was happening to their brother. Parents were reported to have been the main source of the information for the siblings, however, eight of the informants said that they were not given enough information to understand what was happening to their brother:

> Q. Did anyone talk to you about what was happening to Cameron?
> A. Not really. I think they [the doctors] talked to my parents when I wasn't there. My mom did kind of explain that he had a brain injury and he might be affected by it… that was about it….I was really worried about him, I didn't understand what was wrong. (02)

> I think there was one thing that they [parents] told me. I think that it was that he couldn't move his arm or leg or that he couldn't walk on his leg, or that he couldn't use his arm very well….I kind of felt sad. [I wondered] whether, maybe Cameron was going to be like that all the time or whether he was getting better…or if he was getting better or…getting worse. (02)

> No, no one talked to me. Even when I was at the hospital no one there told me anything about Allen. (01)

> Like I didn't know what was going on, when I asked them I got…I was scared someone was going to die, I didn't know who it would be, but I was scared of most things…It wasn't like they sat me down and told me, they just kind of…`Oh, we are packing our bags, we're gonna go away for a little while' and `Scott is very sick and that is why we have to go.' `We are gonna go to the hospital' and they tried to make it all nice and cheery but it really wasn't. (02)

Three informants reported that in order to get more information about their brother's condition they tried to piece together information by listening to parent's

conversations with other adults and listening in on their parent's telephone conversations:

> Q. Did your Mom or Dad talk to you about what was happening to
> Cameron?
> A. Not really, but I kind of understood what was happening….I would
> overhear my Mom and the doctors talking away ….I kind of had to try and
> figure it out by myself. I could listen…like I would pick up the phone and
> my Mom would start talking about it and I'd listen in and find out that
> Cameron did have a brain injury…(02)
>
> Yeah, that's where I got most of my information from, was like other
> people talking….Yeah, I don't know, adults…I think they tend to forget
> the kids and just kind of talk amongst the adults. (02)
>
> Like I would hear them talking and I would be listening and `Oh, well, that
> sounds right' and I would put all the conversations together and then I
> would ask my Mom about it and she would probably give me one-fifth of
> the information she gave to each different person, you know. (02)

Being Ignored

Five informants reported that they felt ignored by the doctors and nurses when

they visited their injured brothers:

> They just talked to the adults. It was like I wasn't even there. (06-1)
> Nobody ever really talked to me about it, they'd be just like, `Oh, here is
> his little sister'….I would be standing there feeling like I wasn't even there
> but I was, like people didn't even notice me. They'd know I was there but
> they didn't look at my face. (02)
>
> My Mom was the only one who ever talked to me about what was
> happening. When I visited…no one else said anything to me or paid any
> attention to me. (01)

Given Worse-Case Outcome

Three informants were upset at what they perceived as the total negativity of the

doctors about their brother's prognosis. They felt angry that they did not present even the

possibility of a more optimistic outcome for their brother and refused to accept the

pessimistic outlook:

Some doctor…he was saying that like Kevin wouldn't be able to walk or anything like that and he, `Well, basically he will be a vegetable. 'Like I don'' know. I didn't like it…it was like it was so wrong because Kevin walks and stuff now. It just made me mad 'cause like…I don't think I heard anything really positive from any of the doctors or anything and …I don't know, I think it would have been better if…like instead of just giving the worse case scenario they would give like…`Oh, well, either this or I guess this'. (01)

It was really negative comments. Like `Don't ever expect  anything out of this kid.' Like `Nothing is ever going to come out of this'…. 'cause they didn't give, well to my knowledge, none of them gave a positive comment for the whole thing. And, yeah, it was pretty much all negative. I wouldn't mind the negative so much if they gave a positive AS WELL with it.…I was mad, but I was just a little kid so it's not like I could do anything about it or…I was pretty angry about that. (02)

Now he [the doctor] took us in a little room, in the emergency room, and told it to us straight, `In the next 24 hours he could live or die' and negative stuff like that. That was really upsetting. I wouldn't believe that he wouldn't be OK. (02)

In summary, one informant was only three years old at the time of her brother's injury and had no memory of the event. All other informants recalled quite clearly the event of learning about their brother's brain injury. Those siblings who received no information or only partial information and felt ignored by doctors and nurses reported more uncertainty and fear. Experiences of being kept in the dark, being ignored and given the worse-case outcome as siblings learned about their brother's brain injury are the antecedent conditions to the process of the sibling's changing lives. These precede the action/interactional strategies which were used by the informants.

Action/Interactional Strategies

Action/interactional strategies are those goal-directed, processual strategies

undertaken in response to or in order to manage a phenomenon (Strauss & Corbin, 1990).

During the process of changing lives as a result of learning about their brother's brain

injury there is an initial phase of realizing their lives are different. The

action/interactional strategies undertaken by the informants as they realized their life is

different were experiencing disruption to their normal routines, becoming re-acquainted

with their brother, and experiencing changing roles and changing relationships. The

second phase is one of adjusting to the changes and the action/interactional strategies

employed were distancing, seeking support, altruistic helping and emoting.

Realizing Life is Different

Siblings experienced a sense of loss as they began to realize that their lives were

different than they had been before their brother's injury. Life was different as a result of

the disruption to normal routines, having to become re-acquainted with their brother, and

their changing roles and changing relationships with their brother, family and friends.

Disruption to normal routines

The normal routines of all of the informant's lives were changed as a result of less

time with their parents, the extra time they spent visiting at the hospital, loss of their

brother as a playmate and loss of time with friends. Eventually when their brother came

home from the hospital the disruption of their daily activities by the brain injured brother

and the necessity of adjusting family activities to accommodate their brother disrupted

their normal routines.

Loss of time with parents. Informants reported that parents were occupied with the

injured brother leaving the parents with less time to spend with the informant. Many

informants stated that they understood that their injured brother needed their parent's

more than they did but that did not lessen their disappointment:

> My Mom was at the hospital from morning till night. She did not come home much at the very beginning....I didn't see her much because she would come home really late and I was usually asleep. (01)

> Well, it was very hard because, first of all, Mom would be gone and then she would be home and then my Mom's mom, she would be gone with Allen.... And Mom was usually gone for a week at a time. Dad was here and if Dad ended up working late or something I was over at Grandma's. (01)

> Dad and Mom were always up there [at the hospital] and I was always with friends.... It was kind of neat [at first] because I'd get to do whatever I wanted, `cause you got spoiled by your grandparents, but it was weird because you didn't see your parents as much.... Yeah, [I understood why they had to be away so much] `cause I knew they had to be with him, but...(02)

> ... sometimes, like I was in hockey tournaments - they'd [his parents] always ship me off with other people to go to hockey games... it was disappointing when I scored a goal or something else good... it was like so what, they weren't there to see it, I'd have to tell them. (01)

Several informants perceived that the stress and time commitment of caring for

their brother caused the loss of time with a parent to become permanent:

> Q. Has your brother's injury affected the time you spend with your family? A. Yeah. It's a lot less.... Me and my Dad used to go horse riding all the time, now we don't. Me and my Dad don't do many things together any more. [crying] (01)

> I think I would have liked...I think I would like it if I had more time with my Dad and just...`Cause, well he is pretty busy in the first place and it [having to look after his brother] just kind of puts the cork on it, I don't know....Like there is lots of time spent on Kevin like from both of my parents, and it just kind of leaves me alone. (01)

Two informants accompanied their parents to the hospital whenever they visited their

brother, and therefore they spent more time with their parents during this period but still

reported that they spent less time with their parents for normal activities.

Extra time spent at the hospital. Informants reported that they felt their normal

routines were disrupted because of the time they spent at the hospital:

> In the beginning it was a real down, I guess, just so much time at the hospital and stuff like that.(02)

> It was kind of a weird time because I was bouncing between school, roller hockey and my little brother [at the hospital] and I was spending most of the time with my brother….I felt kind of out of place, like I didn't know whether to go to a hockey game, do my homework or see my little brother in the hospital. (01)

Loss of a playmate. Three informants talked about missing their brother as a

playmate while he was in the hospital, and said that it wasn't the same when he came

home:

> Q. What was it like at home when Cameron was in the hospital?
> A. I don't know. It wasn't as loud. He wasn't there to play with me…I didn't always have someone to play with [when he was in the hospital]…before his injury I had him to play with….When my friends came over and Cameron didn't have a stroke he could do a lot more things, And now that he can't do a lot more things they realize that….Kind of like when we would play `Pig-in-the-Middle' downstairs they could tackle him and now they can't because he has his arm. (02)

> It is a little more harder to play with him because his left hand is still a little weak and he has to learn to use it again. (01)

> [Before the accident] we always went boating and skiing together. We spent a lot of time together….Yeah, that changed after his accident. (02)

A fourth informant reported that she would like to be able to play with her brother more,

but he sometimes spoiled things she was doing so she really couldn't count on playing

with him:

> Sometimes we have fun playing ... but sometimes he breaks my things, like when I built a snow fort and wanted him to come play ... he smashed it and then I couldn't play in it either. (01)

Loss of time with friends. Disruption to normal routines, especially in the months immediately following the injury, resulted in less time for friends for all but two of the informants. Some informants reported that they continued to have less time for friends after their brother came home. In several instances they chose to spend more time with their brother and to assume additional responsibilities. Others reported that it was expected that they would assume added responsibilities, thus reducing time for activities with friends:

> I definitely wasn't as active but I concentrated on the necessary things…[I gave up] a little freedom 'cause of the added responsibilities at home….At the time Mom and Dad were going every which direction. You just took up where it doesn't go…I didn't have as much time for my friends. (01)

> I have slowed down some….Sometimes [my friends] will just be like "Come skateboard, Justin", and I'll say "No, I promised I will do something [with Cameron]. I have to watch a movie with him. (01)

Anne reported that her entire family concentrated their time and energies into managing her brother's recovery and had little time for activities outside of the family.

> When I was home… I didn't socialize as much. We kind of kept to ourselves, or I did… I stayed home more…. 'Cause I wanted to be with him and [long tearful pause] I couldn't talk about things [for about a year]. (02)

Chad explained that after his brother's brain injury he was expected to give up a lot of activities with his friends in order to help care for his brother, but he wasn't resentful. He accepted what he had to do:

> It [my life] is very different, I have had to make quite a few changes in my

life. I have had to give up [long pause and sigh] the hardest part would be with having him this way is a lot more lifting. And the hardest part for our family is there are only two with the strength to lift him…'cause he is getting quite heavy. So it is me and Dad that do the lifting, so when Dad's at work I am the one that gets stuck with all the lifting…. Well, before the accident I used to do lots of skiing. And I used to go out to friends and we'd go skidooing in the winter and in the summer we'd go quading and dirt biking and like that, and I sort of had to give that up too. (01)

I sort of thought, `Well, if it has to be that way, it has to be that way.' I just accepted that things had to change. (02)

Disruption of activities by their brother. Other changes to normal routines were experienced after their brother came home from the hospital. Two siblings talked about how their activities were sometimes disrupted by their brother. Tammy explained that she spends more time by herself in her room:

It's because I like reading books and that's hard [now] when Cameron is around. (01)

Brenda described how Bruce interferes with her and her friends when they are playing:

Well sometimes he is more mean by taking my toys away when I play with them or when I am playing with my friend. He always comes in and we're playing with some toys, he always takes them away from us…. I feel bad because, sometimes he takes only my friend's toys and then we can't play and she goes home. (01)

Adjustment of family activities. Siblings explained that their daily routines also were changed because the family had to make adjustments to family activities to accommodate their brother following his brain injury. Informants described that the family had to take their brother's physical limitations into consideration when planning family activities, some families no longer did as much together as a family, and family activities were frequently curtailed because of their brother's medical problems:

We are a lot more careful around him now....because before we used to, me and my brother, used to play fight a bit and he'd end up getting hurt, but now, you know, we don't ....We all spend more time with Cameron. Now instead of Cameron running around and getting into trouble, or what not, he still gets into a little bit of trouble, but usually he slows down and we have to wait for him and help him out and stuff like that. (02-1)
We are a lot more cautious of what we do with him. Like if we go to the mall we can't park too far away `cause Cameron will get too tired. Or in Disneyland Cameron couldn't walk that far so we would have to sit down, take a break way more often. (02)

Everyone in our family loves skiing, but that [winter] was going to be his first time and so we were going to take him out skiing. But then the accident happened and then we knew that we wouldn't be able to [have a family skiing trip]. (01)
Well, things [family activities] have changed a bit because in the fall it is cooler and we can't take him out [with us] because he is usually on the ground. The ground is so cold we don't want him getting sick. In the spring when the cows are calving it is a little harder to take him out. When we are feeding it is harder to take him out because...it wouldn't take much for him to get run over. So, usually Grandma stays with him. (02)

[Kevin's injury] puts my parents under a lot of stress because they have to take care of him all of the time ... I think it [long pause] `cause it has made me pretty self dependent I think ... like I do a lot more things by myself now. (01)

He always had a headache. We'd go shopping. You'd get to the mall, you'd be at the cash register, Mom's ready to buy me something, she has to put it down, go home right away....But it was always made up to me. They took me out again...but at the time it was just so frustrating, made me cry. I cry lots. (01)

Disruption of family activities surrounding special occasions were especially

difficult for two informants. Trevor talked about how upsetting it was to have to celebrate

his birthday away from his family. He commented that he still remembers how upset he

was because he was camping with relatives, and his parents couldn't call to wish him a

happy birthday:

Um, [long pause] like they tried to be I guess there for me when they could, but for the first little bit like it was really hard for me `cause I had to spend my birthday with my aunt and uncle and like it just wasn't the same. I don't really remember much about it but I was upset and I've never forgotten that birthday. (01)

Dan remembered the Christmas following his brother's accident. He realized that his parents were postponing the family's Christmas celebrations because Brad was still so sick, but nevertheless he recalled being very upset:

> ... it was Christmas time too, so we spent Christmas at the hospital, that was hard for me `cause I still wanted my Christmas and that couldn't happen or anything ... They told me that we would have Christmas later when Brad was better, but we didn't know how long that would be ... it just didn't seem right. Christmas is special. (01)

Unexpected company. Many of the siblings recalled how relatives and family friends came to the house to look after them and try to keep daily routines as normal as possible for other family members. Most siblings enjoyed the extra attention. However, for one informant the sudden arrival of relatives and the resulting disruption to normal routines caused her to worry even more and made the situation with her brother seem more serious:

> I didn't know what was going on, like I don't know...like everybody, all of a sudden my relatives that I hadn't seen like ever and they were coming that live in Ontario and from the States and I met cousins that I'd never met before and all these aunts and uncles that I'd heard so much about when I was younger also came. I didn't know what was going on. I didn't know why everybody was all of a sudden came and all of a sudden then...my parents were gone to Saskatoon and I didn't know what was going on. I was just wondering what was going on and why it was happening and what I didn't know. I was just wondering what was going on and why it was happening and what was going to happen, was he gonna die? [tears] I didn't know (02)

Becoming More Responsible

Daily routines changed for some siblings as they found themselves becoming more responsible than they had been before the injury. Assuming tasks around the house was one way they talked about becoming more responsible. Others explained that they felt more responsible for their brother's welfare.

> Mainly the cooking, looking after my younger brother and stuff, making sure a meal was ready when Mom would get back from the city...it was just part of helping out in things, that's the way I felt. (02)

> I spend more time looking after my brother, doing things for him. I have become more responsible in that way. (01)

> The reason that I worry about him sometimes is that there is this kid...down the block and he's like crazy or something, he just goes all out. Like he bounces on our trampoline a lot. He's seven years old and he can do back flips and everything, and front flips, and I'm afraid sometime he is going to encourage Cameron into doing something like that and I know Cameron can't handle it. I feel that I need to protect him to keep him from getting hurt. But I'm not always around. (02)

Because of the responsibility of looking out for his brother one informant made changes to his normal routines to minimize the possibility that he might have an accident that would prevent him from looking after his brother:

> Yeah, I skateboard but I've really slowed down on skateboarding because if I hurt myself then no one will be looking after my brother if I guess I'm not around or my parents are not around....I try not to get hurt that much. (01)

Loss of time with parents and the arrival of unexpected relatives immediately after the brother's brain injury cause a great deal of distress. The sibling's age at the time of the injury had no apparent influence on the amount of distress experienced.

Becoming Re-acquainted

As siblings experienced the disruptions to the normal routines of their lives they began to realize that their brother had changed in many ways. They became aware that their brother's personality had changed, that there were physical and cognitive changes and often frustrating and inappropriate behavior, which necessitated becoming re-acquainted with this "new" brother. One sibling explained it this way:

> Yeah, it was weird, like a piece of you had been taken away and you have to learn this new piece, all different. (01)

A different personality. Two younger siblings reported that their brother was frequently more physically aggressive after his brain injury:

> He has a bad temper. He can be mean to me sometimes (01)

> Sometimes he's more mean to me and sometimes he's not. It kind of makes me sad and sometimes he is really really mean to me and I don't like it so I tell him to stop. But sometimes he doesn't. [Before his injury] he wasn't as mad at me and he was really more nice to me sometimes. And ... he wasn't as mean to Peter. (01)

Others commented that their brother's personality improved as he became more outgoing:

> He was always secluded. He always stayed up in his room and studied. But after his accident he learned to come out more and stuff.... I think it's been good for him, like not good... he's more open to people now and he tries to meet people and stuff. Before he wouldn't do that. (01)

> A lot of people have told me he's changed. I don't know. It's just the way I've seen it in his personality..... Like he has come out of his shell a lot but the person that I know now, we were out at... a formal on Saturday night and he was up there dancing and even had a date there and everything but I can't see the old Brad would have done that. So it has given him more confidence, I think, or a new confidence, so in that way it's good... (02)

> He had sort of a whole personality change when he came back from the

hospital.... He acts more responsible, he acts more mature.... Before he had his little stuff... now he wants to go out and have some fun. (01)
Before he wasn't really a social person, he would sort of go down and go to his room and just hide all day and not do anything and now he comes out and he's more of a social person and he wants to go and have fun more and before he would just rather sit in his room and play nintendo or read a book or comics or something. (02)

Physical changes. Nine informants identified physical changes in their brother

which caused changes in the way they were able to interact. Siblings discovered that their

brother could no longer keep up with activities or was no longer interested in activities

that they had previously shared:

> Yeah, it is a little more harder to play with him because his left hand is a little weak and he has to learn how to use it again.... It's different, he is a lot less active.... It's   a lot different because now Cameron watches a lot of TV, like, he has probably memorized the whole TV channels and what not. (01)
> He is a lot less stronger. He has to learn to redo everything using the opposite [side] of his body.... he is a lot less mobile than I am. (02)

> He gets really tired out fast. It makes it hard for him to keep up with us. He gets very, very frustrated very easily because he knows what he can do and he is not able to do it because he gets tired so fast...it makes it worse for him. (01)

> He was different. I wasn't understanding what was wrong with him. Just the way he looked and the way he acted. Like the way he talked and walked, it was just so different than before. [voice choking] I didn't know how to deal with that.... Well I know he's not normal but like he looks normal now, except for his eye, but lots of people have a lazy eye. (02)

> He is different [than other brothers] because he can't tell me what he wants. Unless he is using sign language but I don't know all of it. (01)
> ... and he's got this chewing problem, he can't stop chewing, he wrecks all his toys and, well, he's active, he's not as calm as the other children, and he definitely interrupts! (02)

While the informants appeared to understand that these changes were as a result of the brain injury and might be permanent, they often expressed the hope that their brother would eventually regain his previous pre-injury state. One informant explained his understanding of the permanence of brain injury, but later expressed his hope that his brother would eventually completely overcome his disability:

> It means like if your brains ... when you get hit by a car your brain gets affected and that part of your brain it can never...almost like not...it can't never be repaired or anything your whole entire life. It is like a(n) arm, if you lose a(n) arm you could replace it but you can't replace your brain .... John acts like everybody else, except from the crash his foot turns in like this, `cause it's from the crash .... I think his brain is going to heal before he's grown up. I hope it does .... I hope that his foot is not always crooked like that...because people make fun of him like that and they say `your brother runs weird' (01)

One young informant talked about how it upset her that her brother had to look different than other children. She did not understand why her brother had to wear a helmet when other children did not:

> ...it is hard for him to do things , some things....Some activities at school, like sometimes when they go skating or skiing, Cameron has to wear a helmet and I don't think that is very right. (02)

Cognitive changes. Seven of the informants recognized cognitive changes in their brother following his brain injury. Siblings were upset and frustrated as they realized that, their brother had little memory of his life before the injury, and sometimes he thought that he remembered events that had not actually occurred. Also he was much slower mentally and had difficulty learning new things. They described how these changes affected them:

> It's hard ... I don't... I try not to fight with him as much but sometimes you have to. Because he has these ideas about things that are not right and you

try and tell him that they are not but he doesn't believe you and then things like that. UM, he ... I don't know what the word for it .... He gets ideas and stuff and he thinks they happen and they don't and then he is sure they happened and he keeps pushing it ... yes they happened, yes they happened, but they haven't [long tearful pause]. It's hard to handle 'cause his childhood's gone, his memory is gone. He gets depressed and stuff, at times ... he can't learn how to get back on track by himself, he needs guidance. (01)

Some things are hard to deal with. 'Cause you've seen, like it's his ... for him to work it out is so frustrating 'cause before he was such a whiz (snaps fingers) about everything and he got everything just like that and now he has to struggle with everything and it takes him so long ... it's difficult ' cause I want to help him but I can't. (02)

He is different, he's not the same any more at all. He is not as intellectual as he was before .... He does have a hard time with his school work, where before it came to him like nothing. He gets headaches really bad and he can't ... when it comes to ... like (01)

Frustrating and/or embarrassing behavior. Eight informants reported that they were frequently frustrated by behavior changes in their brother following the brain injury. They often did not understand why their brother's behavior was so different and at times inappropriate and unpredictable:

Q: What is it like having Cameron for a brother?
A: Sometimes it's frustrating, sometimes it's just happy and sad. [It is frustrating] when he gets all mad at me and starts taking things and starts trying to hit with them .... He didn't do that before ... I don't know... (01) ... if some TV program is on or something he will start to cry and I will get mad. Because he shouldn't be crying when there is nothing to cry about. (02)

He's fidgety. He is always shaking or banging something, he's got to be doing something. You sort of just say 'sit down and take it easy!' But he...sometimes he just can't. Sometimes it makes me angry....He'll talk nonsense about something that he'll have no knowledge about or anything. You'd just get frustrated about half, some of the time. I think sometimes it's attention. Sometimes I don't think he knows better, so...that's

frustrating, not knowing which. (01)

Sometimes if he is tired, or I don't even know if he is tired, but he does get kind of goofish and not to his age level and at that time you just take him aside and talk to him.... Sometimes his sense of humour too. He is very childish. It doesn't make sense to him. (01)

...I'll tell you it [his behavior] is just this different. I don't know what to do with him because if I want him to do something with me it's kind of like... maybe or maybe not. It's still hard to know what to expect. (01)

It's kind of boring sometimes, because he is never really wanting to do anything. He is afraid that he might hurt his hand or he gets tired really easy, but sometimes he is really active... and he is just like every other normal kid. I never know. (01)

Like I kind of get frustrated with him not being able to go as fast as I would like him to or get into the car quick or anything like that. I don't know, it is just stupid little things like that, it is hard to... (01)

Two informants described how their brother's behavior was not only frustrating but often frightening:

... when he was mean sometimes, like chased me around the table and grabbed the knife or something. But.. .and then he only did that[grabbed a knife] once but he... I don't know, I just know that he is my brother and that sometimes he gets agitated.... He wouldn't listen to me, it was frustrating. (01)

... at first we didn't get along at all. Like he kind of got into a violent state and I just couldn't... not really talked to him or anything, and now... it's a lot better. (01)

The same sibling worried about how other people would react to her brother's inappropriate behavior:

He, I don't know, I don't think... well, he does dumb stuff... Like he will be joking around or something and it's like `Oh God get away from me!' He just gets hyper and dances around and... but it's like `Oh God, don't do that!' Or he will go up and talk to some stranger and you're like `Oh my God don't.' Or he'll just do something out of the blue like, I don't know

how to explain it, like, he'll just start wrestling with one of my friends and they don't even know him. And like, `they are never going to come back here again!' (02)

As siblings realized that their brother had changed and was no longer the same person that he had been prior to his injury, they began the process of becoming re-acquainted with this "new" brother. They had to become re-acquainted with a brother who may have a different personality, physical and cognitive changes, and sometimes frustrating and inappropriate behaviour and did not fit into their lives in the same way he had before. They learned how to adjust their lives to accommodate their "new" brother.

Changing Roles

As siblings became aware of the many changes in their brother and began the process of becoming acquainted with the "new" brother, they experienced changes to their roles within the family. Siblings took on the role of protector, assumed parenting/caregiving roles, acted as coaches in their brother's recovery, and younger siblings found themselves assuming the role and responsibilities of their older brother.

Protector. The role of protector was one siblings took on willingly and some spoke of the need to be responsible for their brother's welfare in the future:

I watch out for him a lot, more now than before. If he is tired I will tell him, `take time out if he is getting into an area where I know doesn't seem right. Like relationships-wise and what not. I'll let him know...just watching out for him. When he's going out with other friends and just trying too hard to fit in but sometimes you know he's trying too hard and the other people aren't letting him fit in. So you have to sort of let him know what to do, how you feel about that.   (01)

I feel that I need to protect him to keep him from getting hurt, but I'm not always around. (01)
It is pretty natural when you have a little brother you want to look out for

him, to make sure he doesn't get beat up or anything. Now more than before. He is a lot less stronger....I kind of fear that Cameron won't get a good enough job or something when he is older, enough education, he might suffer a little bit. So I need to get good marks and maybe support him when he is older....he won't be qualified for any of the better jobs so I will have to support him with my money. (02)

Well, yeah, I do worry about him because...we have kids in school, lots have become bullies to kids in his grade and I just hope one day they don't get bullying him around because they are not going to expect what is going to hit them. (01)
I sort of know that I am always going to have some responsibility for him...having to work with him...or having to help him with anything....I will do it, if it keeps my brother so that he didn't end up...I'll look after him. (02)

I worry about him having friends and being picked on and stuff like that I watch out for that. I am always ready to beat up somebody that is picking on him. It makes me feel angry. (02)

<u>Parent/caregiver.</u> Four informants assumed some of the parents' responsibilities

and/or became caregivers to their injured brother:

...there are only two [of us] with the strength to lift him...So it is me and Dad that do the lifting, so when Dad's at work I am the one that gets stuck with all the lifting. And when Dad gets home we just sort of divide it up. There's sometimes at school...there was one time when he had this walker and all of a sudden nobody knows what happened but he just fell and his one arm got caught in the walker and they didn't know if he broke it or whatever. My Mom works part time, so they called me and I went out there....I spend more time looking after my brother, doing things for him. (01)

Oh, I helped feed him. I helped with his sheets and stuff and like everything that Mom and Dad did to help him, I helped him out....At the hospital I told them to bring in the speakers for his Game Boy so when he was in the coma he could hear the music and stuff from the Game Boy. (01)

I keep house...do the laundry. I'm sort of the woman of the house...it is kind of hard, Tom doesn't do anything in the house. (01)
Yes, like in the hospital I'd always help him walk down the hallway or get

into his wheelchair. [At home] I'd help him get out of bed in the morning and come up the stairs here and help him get breakfast ready or whatever and if he needed help [with breakfast] I'd help him. (02)

Coach. Two informants took on the role of coach. One sister encouraged her brother to keep trying when he became discouraged and coaxed him to participate in activities:

> It makes me feel sad. One time when my Mommy came home my brother wanted to tell her something really fun that had happened and he couldn't say it...so Mommy and Daddy couldn't figure out what he was saying and then he just said, 'Oh well, I tried.' So now when he tries to tell me something I say 'Bruce, don't give up! Don't feel that you can't say it cause you can!' .... We like to play games together...sometimes he gets it wrong but I don't mind, I just tell him the right way to play....If I teach my brother to be happy, then if he grows up and has children he can teach his children how to be happy.... Sometimes if I want to play something and he doesn't then I make funny faces and he likes it, he laughs. (01)

Another sibling said that it made him happy to be the one to help his brother with his homework:

> I feel good about being able to help him. When he comes home and he's got a little bit of homework I usually do it with him. I make him do all the calculations. Usually he's got little pieces of Lego and I just lay them out and he picks out how many he needs and he puts them in individual little piles and counts the ones he's got, and if that equals the question that's right he puts it down. You can see that he is just getting better and better. It makes me happy that I can help him get better. (02)

Eldest sibling. Three of the four younger siblings reported assuming the role and responsibilities of their older brother. They all talked about feeling guilty at times for having to take over their brother's normal place in the family especially when the brother did not understand why it was necessary:

> It seems like I've had to take on the role of the eldest in the family...'cause

like he can baby-sit and every thing but my parents don't like leaving him here because he argues a lot and it just seems...I don't know, they don't want to leave him in case anything happens and they wouldn't know what to do...so that I have to...even though he is older than me, I have to stay home sometimes even though he is here. And sometimes he gets angry because he thinks I think I am baby-sitting him too....My parents talk about it [Scott's injury] together and sometimes with me, but they don't really explain it to my younger sisters and brother because they think they wouldn't understand They would understand but they try to act like it didn't really bother them with my parents. So I try to explain it to them because I know they are really worried about it. (02)

...I definitely had the big brother role...I sort of still do, actually though, just watching out for them...looking after Dan and stuff. It kind of felt good because I was taking the big brother role...but Brad didn't like it, he just couldn't understand... (01)

One sibling expressed mixed feelings about having to assume her older brother's responsibilities:

He would have had to clean and stuff and I would have got to go play and do whatever I wanted when I was little but I had to do it instead of him. It was different because I didn't get to go play in the sand and fool around and be a normal kid. [Sometimes] it was neat because it was like I had a little brother, that was kind of neat. (02)

Changing Relationships

As siblings experienced changes in their roles and began the process of becoming re-acquainted with their brother they experienced changes in their relationships with their brother, other family members and friends. Some relationships became closer while others became more strained.

Closer relationships. Eight informants described a closer relationship with their brother following his brain injury as they became friends, as they made more time for their brother, and as they made adjustments for him. Three informants spoke in general

terms about becoming friends with their brother:

> Like we are friends now...so...that makes me feel good. I never did have him as a friend and it feels good. (01)

> We are a little closer, better friends. We get along better...we can sit down and talk to each other without strangling each other. (02)

> I have come very close to my brother within these five years since the accident (01)

Five informants explained that they developed a closer relationship with their brother as they tried to make up for their brother's loss of friends following his brain injury. Others reported that their brother can no longer keep up with his friends and that they often leave him behind so they make an effort to include him in their activities:

> [Our relationship] it has changed a lot. We have become pretty much really good friends over the last while because of his brain injury....It is a lot of fun with my brother. Cameron's friends maybe aren't as patient with him. He gets left behind. I kind of try to make up for Cameron's friends....He is not afraid to go along with me and I don't care if my friends see me at the mall with my brother, taking him to a movie. (02)

> Scott and I can share a joke that nobody understands. Like we have insider jokes....If he had been healthy he would have been out more...had more friends. They would have gotten closer to him. I think that is why we are closer now. (0 1)

> Um, I feel a little bit scared because I think they [other kids] are gonna get mad at my brother...so then, I feel scared that he is not trying to say anything. But I know he is trying, but they go away and the only person left to play with is me so I play with him. (01)

> All of Brad's friends have pretty much left him, or a lot of them don't even keep in contact....It hurts and stuff to see that he had to make a whole new bunch of friends..... We probably spend more time together as a result .... We talk to one another a lot more regularly...over all we talk about mainly problems and problems he is having, we're a lot closer. (02)

> ...kids that were his friends before he got hurt but after he got hurt they are

not his friends any more We are closer. I probably get along with him better now. I probably like to take time to do stuff with him because of that....Sometimes I will take him to the movies....I will take him out and stuff and he is always on his best behavior and he is just, he is like proud to go out with his sister. (02)

Five informants reported that their families had become closer as a result of their brother's injury.

Our [family] relationships have really become closer.... Pretty much the whole family. We have Grandma and Grandpa and my other Grandma, nieces and nephews and cousins, my Dad's brother.... They are all really helpful. (02)

Our family is closer now. We do more family activities than we used to. Like getting together for dinner on Sundays. We always do that now.... We can talk about how we feel more, not everything, but some things. (02)

Five informants said that their relationship became closer as they made more time for their brother and made a conscious effort to find activities they both enjoy:

Now we find more things in common and stuff like that. I try to pursue those things more so we can find things that get along with and do together....It makes me feel good because I know he is enjoying it and I am enjoying it and we get along and stuff. (01)
There is not really a change in [either of] our activities, it's just we do those things together now, we both did them before but now it is somewhat more together. (02)

[Before the accident] we fought all the time. I don't know, before we weren't as close as we are now. He had his own separate crowd of friends....Now we do a little bit more together, a little bit more. If he wants to come he can and if I don't want him there I just tell him...but he's always wanting to come out with my friends. (01)

Now I think I spend a lot more time with him...because when he didn't have his brain injury it didn't really matter that he didn't have an injury. But now it does because he has a serious injury...and it is hard for him to do things, some things. So I feel I should spend more time with him. (02)

...before his brain injury I took him for granted. He'd ask me to come and play hockey with him, 'no Cameron I can't, got to go, got to go.' But now if he asks me to come to do something with me I'll be sure to be able to say yes. (01)

...if he wants something I won't hesitate to...to get it for him. And usually I will do things he wants to do...sometimes he will pull out a game that he wants to play. And usually Mom will play with us and we will shut the TV off and sit down and play the game with him. (01)

Making adjustments to accommodate their brother was another way siblings described how they developed closer relationships with their brother. Some informants explained that they couldn't be as rough when they played with their brother. Others adjusted their expectations of what they should be able to accomplish and developed greater patience with his efforts. One informant delayed seeking a goal that she felt that her brother as the eldest sibling should accomplish first:

I don't playfight with Cameron as much now....I noticed that Cameron like to hang around me more and he is not afraid that when he does something wrong I am going to yell at him or I am going to...'Cameron come here' and I'll fight with him...you know that you are not going to do it. (02)

I go easy on him, he can't handle a lot of chores around the house...like you can't really... you can't expect him to help with totally cleaning. (01) When I first turned fourteen I wanted to get my learners really bad but Scott hadn't got his yet. So I was gonna let him get his first because he was older...and I knew that if I got mine first he wouldn't have a chance to get his for awhile. So I was gonna let him get his first and he never got it yet and so neither have I....He has trouble doing some things, you can't just like...'Oh well, I'll do it." You have to let him try and try and you suggest ways to help him out, you can't just grab it and say 'here let me fix it... you won't be able to fix it' you have got to let him try...if I would grab it away and make it 'I will fix it' then he will feel like. 'Oh, I can't do anything and she is younger than me and I can't ...' (02)

Family relationships also changed. Four informants described making more time

for their family, and two informants described improved family communication which

resulted in closer family relationships. Siblings reported that family communication

improved as family members began to share their feelings and experiences and tried to

find ways to help in their brother's recovery:

> We're closer...life is fragile and you can lose it like that, so we try to do more things together and for each other. (01)
> We do more family activities than we used to like getting together for dinner on Sundays. Like they'll [his brothers] come home from university...things like that, just little things. (02)
>
> My brother's brain injury has brought us closer [as a family]...more understanding and not as...we focus in together because you never know when you might never be together...It gave us a greater appreciation for our family. (01)
> We don't take things for granted any more, like .... I am not sure, I just know we are closer ....We talk more. If he frustrates me or annoys me beyond belief I will talk to Mom about it. And if he is doing the same to them they will talk to me and they talk to him about it. That [talking about problems] happens more now.... Brad's brain injury brought me and my other brother together. We are closer. We talk and deal with things more now. He was the only one around so he was there to talk to and I was there for him to talk to, so in a way it was better. Overall, the extra time together brought us I think closer. Once in a while if he's frustrated he talks to me, and if I'm frustrated I talk to him. (02)
>
> Everyone is closer 'cause you've got to help support each other and if one of us is upset we just try to help each other get through it. (01)
>
> The relationships have really become closer...the whole family. We have grandma and grandpa over there and my other grandma, Mom and Dad, nieces and nephews and cousins...pretty much the whole family is closer and helpful. (02)

Strained relationships. Other siblings reported that changes to their lives following

their brother's brain injury resulted in a more strained relationship with their brother,

other family members and friends. They described the reasons for the strained

relationship with their brother as the result of having to be more careful around their brother and increased fighting with their brother after the brain injury. Strained relationships with other family members were described as a result of going our own ways and conflict over the treatment of their brother. Being disappointed by friends' behavior toward their brother caused strained relationships with some friends.

Several siblings believed that having to be constantly more careful around their brother and sometimes having to take on his responsibilities put a strain on their relationship:

> ...a few times I get angry. I hit him in the head... and so I have to watch out, I can't do that no more 'cause I could damage his brain more....It is hard to control my temper 'cause I have the biggest temper in the family and...when we are playing I never think of his brain injury and so sometimes he gets it in the head....I felt like my Dad was going to kill me. It is hard to play with my brother now.... My Dad says that I will regret it if I hurt my brother and he gets another brain injury so... (02)

> We used to live on an acreage...And he was not allowed to operate a motor vehicle, tractor, lawn mower, or anything like that...I had to do it...cut the lawn, because Mom and Dad couldn't do it. So it made me feel like he was gettin' along pretty easy sometimes and he was playing it. He managed to get out of most things. It made me really angry that he got away with that. (02)

Two of the younger siblings who had previously good relationships with their brother said that they fought with their brother more since his brain injury:

> Before the accident we got along a lot better 'cause when he had the accident...like I don't know why we got along better then but we just fight more now. (02)

> [Before] he wasn't as mad at me and he was really more nice to me...he wasn't as mean to Peter. Sometimes I get really...when he bugs me too much I accidentally get too mad and try to beat him up. (01)

Two informants described relationships with other family members as more strained

because the immediate family members went their own ways after their brother's brain

injury:

> We're not as close I guess. The family as we've grown on, we've sort of
> gone our own ways and stuff....My Mom worries about him a lot. She's
> always concerned for him...she is not herself a lot of the time. Dad worries
> too, he seems to work even more now. (01)

> It puts my parents under a lot of stress because they have to take care of
> him all the time. And with having to work too...I do a lot of things for
> myself now....the stuff I am interested in, it is not anything to do with
> them. (02)

A third sibling described her immediate family as being very close but explained that

relationships with extended family were more distant since the accident:

> ...because our family is just us four. Like no one else really gets involved.
> Like Grandma and Grandpas...like no. Aunts and uncles no.... My Mom
> and my Dad they've both been there [for me]. Since Jim's accident no one
> else has been there....I will talk about it [problems with her brother] with
> my parents...really it is not anyone else's business. I don't think any of my
> friends or relatives understood that much. (01)

Only one sibling talked about strained relations with his parents over the parents'

treatment of his brother following the accident. He explained that it bothers him to watch

his parents allow his brother to do what ever he likes. He expressed concern that in the

long run this will have a detrimental affect on his brother, but he eventually stopped

trying to discuss it because it had become a source of conflict between he and his parents.

He explained:

> Well during the week we are supposed to be home between 10:30 and 11
> o'clock because both Mom and Dad go to bed really early and they don't
> sleep until we get home. And there are lots of times where he doesn't even
> come in the door until 3 or 4 o'clock in the morning and they don't say
> anything to him at all and if I do [say something] it just hits the fan...they

don't want to put any stress on him. Because they figure the more stress the longer it will take and the problems it will cause....there is no talking about it. (02)

Two siblings were upset by the reactions and behavior of some of their friends following their brother's brain injury which resulted in strained relations with these friends:

...at first it was embarrassing because everybody was talking about him... 'look at the way he walks' and 'his hair- what kind of hair is that' it was embarrassing, but after when I saw that it was really bothering him I was pretty upset about it. Because most of the people saying it were in my grade and I'd known them for a long time and they knew that was my brother and it was so upsetting.... [tears] (01)

The same sibling reported that some of her classmates felt that she exaggerated the seriousness of Scott's injury to get special treatment and so she stopped talking to those friends:

The ones I talked to they understand, the ones I don't talk to anymore are like... 'cause they will say over the intercom [at school] to say a prayer for Colleen's brother. They will be like, 'Oh, why does she get all this special treatment.' Like the teachers would be easier on me, they would say... ' I understand you are going through a lot.' And they [some classmates] would go, 'Oh, Colleen is just exaggerating the situation.' But my other friends knew...they would be more sympathetic. (02)

In summary, changes to siblings' roles and relationships often occurred concurrently and changes in one aspect often influenced changes in the other. Siblings who assumed new roles to assist their brother were more likely to report improved relationships with their brother and other family members.

Adjusting to the Changes

The second phase of the social process of changing lives is adjusting to the changes. As one sibling explained:

You just have to adjust. You have to learn how best to cope with all the changes in him and ...ways to adjust to the changes you have to make. (01)

As the siblings experienced the changes in their lives following their brother's brain injury they employed four adjustment strategies: distancing themselves from the situation and their brother; seeking support to cope with these changes; altruistic helping; and emoting. Informants reported using several of these strategies over time to help them adjust to their changing lives.

Distancing

Distancing was for the most part an initial means of avoiding having to deal with the immediate situation. Initially, distancing strategies allowed siblings time to absorb the changes that they were experiencing and time to figure out how to deal with their brother's sometimes dangerous behavior. Distancing strategies consisted of ignoring the situation and/or their brother, keeping their feelings to themselves, not asking questions that they had about their brother's brain injury and, physically leaving uncomfortable situations.

Ignoring. Five informants found the way that the only way they could deal with the frustrations they experienced trying to help their brother or cope with frustrating behaviors was to ignore the situation.

At first I just didn't pay much attention to him. Like if he needed help I'd be like, 'Oh, well, just let him figure it out on his own' and I wouldn't pay much to what he did or why he did things 'cause if he was going...like I didn't pay much attention to his interests and I didn't want to get too close because then I would just get more frustrated with seeing him not be able to do things. Like when we go skiing I never wanted to go skiing with him because it would be too frustrating for me and it would be too scary to see him skiing. (02)

...at first we didn't get along at all.... I just kind of...not really talked to him or anything. (01)

I just give up sometimes [when I get frustrated]. I just ignore him. (01)

Other informants reported that when they were upset by other people's reactions to their brother or the way they treated their brother they tried to ignore them.

I acted like it didn't matter to me. I just said, 'Oh, yeah, well, that is the way he is. I don't care kind of thing. 'You can make fun of him I don't care just don't do it in front of me,' kind of thing....It was important to me that they didn't do that so I just kind of, 'Yeah, whatever just don't do it in front of me,' you know. I was very, very upset but...there was all those older people that I couldn't really stand up to because they were like 3 years older than me so... (02)

When people made fun of my brother I'd just ignore what bad things they said....When those things happened I'd just walk away. (02)

Keep feelings to self. Informants discussed feelings of sadness, anger, fear, embarrassment, neglect, being different than others, and worry following their brother's injury. All but three informants reported that their main way of coping with their feelings was to keep these feelings to themselves.

Q. Is there anyone that you talked to about how you were feeling?
A. No. I don't think I'd talk to anyone. I just take it as it comes and keep it buried inside, I try not to let it bother me....Yeah, that's usually how I cope with everything, just keep it inside....I didn't think it was the right time to discuss it [feelings], they [parents] were supposed to be with Brad, that's the way I saw it. (02)

I had nightmares...I never really talked to anybody about them or anything.... I don't talk about things too much. I don't know, I don't think I cope very well because I just kind of bottle everything up and... (02)

I don't talk. I'm not a person who talks [about feelings]. We don't really talk about it, it's kind of put behind us. (01)

Q. Do you ever tell Mommy or Daddy how you feel when Bruce is mean to you?
A. No. Uh, I can't. (01)

Three siblings who were able to discuss how they felt about the changes to their lives reported being able to talk to parents or another close relative or a good friend. They reported that the ability to communicate their feelings was a great help in dealing with their brother's injury and their changing lives.

Not asking questions. The majority of informants reported that they did not receive enough information about their brother's injury or about his progress. They had things that they would have liked to know but did not ask anyone. Several informants reported that they did not ask questions because they were worried that their brother was going to die because they had not been told anything, and therefore, they were afraid to ask about how he was. Some siblings explained that because the doctors had been very pessimistic about their brother's recovery they assumed that their questions would be inappropriate. Younger informants reported that they did not know how to phrase their questions.

I wanted to know if Cameron was going to get better but I didn't ask...maybe because I might have thought it [the answer] would scare me...because they didn't tell me anything. (02)

...it didn't seem right [to ask those questions]. 'Cause I was told kind of, that he will never be the same by the doctors and nurses. So for that reason I didn't want to ask. I didn't want to upset my Mom any more. (02)

When Cameron first had the brain injury the doctor...I was wondering if Cameron would ever be able to...would return to his fully functioning self again 'cause at one point the doctors were saying that he might never walk again....I kind of kept them [questions] to myself. I was kind of curious and confused. I didn't know what to say. (02)

I didn't ask any questions. I was scared of the answers. Like I didn't know what was going on...I was scared someone was going to die. (02)

Leaving. A fourth means of distancing was to physically remove themselves from their brother or from a difficult or upsetting situation. In some instances it was a strategy employed to avoid starting a fight with their brother and perhaps hurting him.

When I feel sad I go upstairs and lay on my bed...I just lay on my bed, like this, and wrap myself in my blankie.(02)

I don't really have much to do with him when he's doing his homework because I know how quickly he gets tired and then he gets upset so I usually just leave....I couldn't beat him up as much because of what I [could do to him]...I just knew that when he was tired or I was mad at him I had to go upstairs where I couldn't touch him. (01)

Whenever hc is in one of his mood swings or in a bad mood, whatever, I just leave him alone, everybody just stays out of his way....When I'm frustrated or angry at him I just go back to work and just let it go, or try to. You just walk away and leave him alone...he goes his own way and I go my own way and finally I will leave the house and I don't have anything to do with him at all. (02)

Just going out and doing something, getting away from him. (02)

Others found it necessary to leave to protect themselves from their brother's violent behaviour.

When he frightened me I went into my room....You learn just to walk away from him, like if he starts getting mad you just leave the room or go outside or whatever. (02)

Seeking Support

A second strategy that informants used to adjust to their changing lives was to seek support. They sought support by talking to someone, sharing their experiences, and turning to God.

Talking to someone. As siblings experienced the changes to their lives they began to talk to others to seek support in adjusting to their "new" brother and the changes to their lives. Younger siblings sought support from adult family members while older siblings turned to friends and other siblings.

> When he gets mad at me and starts taking things and starts trying to hit with them... it makes me feel sad... sometimes when my parents come home I just tell them. I say that it makes me feel bad inside....I have to tell somebody...usually I tell my Mom and Dad....They talk to him...he doesn't listen to me. (02)

> I talk to Mom and Dad about things....If I'm upset or worried I can usually go to Mom or Dad or.. my Grandmother. Sometimes I don't want to worry them so I talk to grandma. (02)

> There were some friends...if there were times that I just needed to talk to somebody about something they would tell me I could come over and they would be willing to sit there and listen. It made me feel a lot better. (01)

> David and I talk about what is happening...not so much when he [brother with the brain injury] was in the hospital but after. Like just lately, just discussing how he acts and what works best. It helps now to be able to talk about those things. It helped to know that I'm not, like not the only one feeling this way. (02)

> ... the only person that I really talk to is my best friend. He's always been .... he's my best friend that I've known since we were kids....He is always there for me, saying, 'it will be ok, so don't worry about it.' (02)

> I had a friend that later ... I just talked to her about everything, like how I felt, everything. I could tell her anything and she would understand ... she made it easier to cope with things after Scott came home ... she knew things weren't gonna go back to normal. She understood what I was going through. (02)

Three informants reported that eventually they sought support from professionals; a psychiatrist, teacher or school counselors.

> Mom took me to a psychiatrist, she took me there so I could get help ... It was about school...I had too much homework and I never got to go outside

... after John's accident.... I think she was really nice ... it made me feel better. (02)

Mom took me to a psychologist after the accident. She knew that I was angry and upset but I just bottled it up. I wouldn't talk to him either. I'm starting to talk more now like with teachers, like counselors at school, but I never used to. It helps ... they are pretty helpful. (02)

Sharing their experiences. Two informants reported that they had recently given a speech about their brother's accident and how it had changed their lives, as part of a school assignment. They described how hard it had been to talk about the subject and how much better they felt when they had finished. They reported that for the first time since the accident they felt that their teachers and classmates partially understood what they had been through and how their brother's injury continued to affect their lives.

Last term I had to do a religion, a literal religion and anything about God. I told my story about my brother and I was bawling my eyes out in front of the whole class and I got to one part... 'cause I wrote it down, I didn't think... 'Oh, this will be easy to read' and I got to the end and I said 'I know most of you will think I am exaggerating this story or making it up as I go but I am not' and when I read that everybody's face, nobody was laughing, like.... 'Trust me we believe you, you wouldn't get this emotional about a lie or anything' and everybody, when I sat down were like, 'I can't believe that. That is a really scary story. I can't believe Heather had to go through all that. She seems so happy all the time, I can't believe that'.... I felt really good. That was about the first time everybody understood. (02)

Turning to God. Three informants reported that their families had strong religious beliefs, and they discussed how they sought support from their faith in God to help them adjust to the many changes in their lives:

God supported me. When they said that he might not make it, right then and there I was praying to God right on the spot that he would make it. And God made sure that he made it.... God has helped me accept the

changes I have had to make in my life. (01)

I pray a lot, a lot, especially now. Any kind of problem, anything... I just think God is listening to what I am saying. It's comforting, it's very comforting. (02)

Altruistic Helping

Altruistic helping was a third strategy many siblings found helped them adjust to their changing lives and the losses that they had experienced. Altruistic helping consisted of making the extra effort to include their brother in their everyday activities, assisting in their brother's recovery, helping their brother learn how to fit in with friends and family, and helping others with disabilities.

Making the extra effort. Informants talked about how they now made a special effort to include their brother in their activities and to make time to do special things for and with their brother.

I try to... find things that we get along with and do things together .... We went to the movies and that made him feel good. We had a good time, (01) Well. we got a ping-pong table for Christmas the year after his accident and his coordination wasn't quite right, so I tried to make time to play with him...I felt bad even beating him, I just kind of let him win. But now he has been practicing...and now I really have to struggle to keep up with him. (02)

...we both talk to one another a lot more regularly .... Overall I make sure I have time to talk ...about mainly problems, problems he is having. I will stop in and talk to him now to see how he is doing. (02)

... since the accident I've always taken my brother everywhere .... I take him to the movies.(02)

We play ... together and colour together, and play my game board, and watch TV.... I get him special things. I like to do that, it makes me happy ... 'cause I can make my brother happy. (01)

Yeah, I do a lot more [for my brother]. He really likes comic book

characters and every now and then I'll go out and buy him a couple of comic books.... I buy him posters and everything.... I will take him to a movie. He likes that. (01)

Assisting in the recovery. Informants described how being able to help their brother lessened their distress and gave them a better understanding what their brother was going through. Siblings helped care for their brother, helped their brother to learn new skills and to re-learn former ones, and helped him identify and correct inappropriate behaviour.

> I don't feel sad when I help my brother...I feel happy. Mostly we have been helping him with his homework. He likes me to help him.... He is not mean to me then. (01)

> ...he has ideas about things that are not right and you try and tell him that they are not but he doesn't believe you.... I just try and tell him... I think it helps him to understand who he was before instead of who he thinks he was. (01)

> ...when he starts to ramble on about nothing that's... you just... I don't know... it would be the same as a younger person trying to convince you about something that you know is absolutely wrong, you know better and you just want him to.... I just talk to him.... I think it helps when he realizes that he is doing it, the other times he will be set in his ways. It's hard sometimes, it's hard for him too, but it helps me to be able to help him. (02)

> A couple of weeks ago I taught him to ride his bike again. He did good. He did it the first time. I felt good 'cause he was afraid to try. (01)

> ...the good thing about helping him is that this last year you can tell he's coming back to his old self because he is putting more words into sentences... he will be watching a movie that he has watched a few times and he will sit there and repeat just about every word that they've said.... You can see you've helped because he is just getting better and better in his speech. I'm real happy about that. (01)

> ... like everything that Mom and Dad did to help him out, I helped him out too. I was as much part of his recovery as Mom and Dad... that made me

feel good.... I am always proud when he does something really good at school or brings home something really nice that he has made or gets a new work experience job. (01)

Helping brother to fit in. Three informants worried about problems their brother was experiencing in trying to fit in with new friends. Siblings felt that they were in a better position to help their brother in these situations than their parents, and they made a special effort to monitor their brother's new relationships.

> You've got to watch that. He's going out with other friends and just trying to fit in but sometimes you know he is trying too hard and the other people aren't letting him fit in. So you have to sort of let him know what to do, how you think about that. I can watch out for these things better than Mom or Dad. (01)

> ... they are not his friends, they are friends when they want something.... I don't trust them... they take advantage of him, you have to watch out for that. (01)

> ... sometimes he gets picked on in school by bigger kids.... his friends they are a lot quicker than he is and some friends... they will be playing in the park and Cameron will just get completely confused... he probably doesn't recognize that maybe sometimes they are going ahead of him or leaving him behind. I try to watch out for that. (02)

Helping others with disabilities. Three informants reported that as they experienced changes to their lives one of the things that helped them to adjust to their changing lives was a new appreciation and understanding for other people with disabilities. They derived a new sense of satisfaction from their relationships with these people.

> I've had more of an open mind to people with disabilities and what it is like for them. I've made new friends, I guess with different people that nobody else really talks with and [I] stuck up for disabled people at school, things like that.... I think it makes those people feel good. It makes you

feel good about yourself, I guess, knowing that you helped someone. (02)

It changed how I see people with disabilities. Like most people... like they see somebody and they say, 'Oh, yuck, gross.' But I help them. Like we had a program at school and there was disabled children there and everybody is like, 'I'm not helping' and I went and helped. It was neat, like it was different 'cause I was helping somebody and it made me feel good because I was helping them. (01)

... some people don't understand anything about disabilities or... like they don't understand why people are like that, or why people have problems. They will say, 'Oh, that persons got problems' and leave them alone. You can't just leave them alone, you know.... I think I am more comfortable 'cause other people don't know how to act. You can't act different, you just act the same. They don't want you to act different around them. It helped me with Scott too. (01)

Emoting

Emoting by crying or becoming angry was another way informants coped with their changed situations. Informants reported that they frequently could not stop crying when they talked about their brother's injury and how it had changed their lives. Five informants became teary and cried as they related their experiences to the interviewer. Others reported that they often became upset and cried when attempting to cope with their brother's behavior.

Yeah, I was always crying in the hospital because I thought he would be like that [always] ... he was talking really slow and funny. (02)

'Cause like it is hard for me to explain to them without like crying or ... getting upset and I get upset and cry most times. (06-1)
I remember walking into the room and just crying, I couldn't help myself.... They had to take me out of the room because I was just bawling my eyes out. I couldn't stop. (02)

When he bugged me I would get angry and just cry.... I cry lots. (02)

One informant described being angry with his brother because he had to assume his

chores and felt that his brother was getting away with more than was necessary.

> He managed to get out of things and then I had to do it. It made me really angry that he got away with that.... we had a tractor to cut the lawn and he wasn't allowed to do that... he used to sit inside and do nothing while everyone else was outside working. I used to just go mad. (02)

Two of the younger informants reported that they usually reacted to their brother by getting angry even though they understood that getting angry wasn't the best way to cope with the situation.

> ... I get so angry with him that I say I wish his brain injury was worse. But I usually don't mean it, I just say that because I am so mad.... We get into some bad fights, like just a little while ago ... first we started arguing and then he hit me and we got in a really big fight and I really hurt him. I know I shouldn't.... My Dad says I will regret it... but I just get so mad. (02)

> Well, sometimes when he breaks something of mine I get really mad at him. I know he sometimes can't help it but I get so angry. (02)

Becoming angry or frustrated with the changes to their own lives and the changes to their brother, and crying as a reaction to those feelings of frustration and anger was a common reaction by all informants at some time following their brother's injury. However, in the above instances emoting strategies became the more frequent ones reported.

In summary, during the process of changing lives four action/interactional strategies of adjusting to their changing lives were used by informants: distancing, seeking support, altruistic helping and emoting. These strategies evolved over time and were undertaken in response to learning about their brother's brain injury. Action/interactional strategies undertaken in response to a phenomenon have outcomes or consequences which may occur to people, places or things (Strauss & Corbin, 1990).

<p style="text-align:center"><u>Consequences</u></p>

Consequences may be events or reactive actions/interactions and may be actual outcomes or potential outcomes (Strauss & Corbin, 1990). In this study, the consequences to the informants of their changing lives were getting on with their lives, either by putting the changes into perspective or a reluctant acceptance.

Putting the Changes into Perspective

The action/interactional strategies of adjusting that siblings employed assisted them to eventually decide that they had to get on with their lives. After a period of time, that varied with each individuals experiences, many informants described reaching a point where they realized that there were both positive and negative aspects to their changing lives and they began to put these changes into perspective:

> On the whole I've come to realize I accept it [changes] good. Not excellent but I've learned to live with some of the things and just try and ignore some of the others that are annoying me .... So overall, I think we've accepted it and are working with it from here on. (02)

> I sort of thought 'well, if it has to be this way, it has to be this way.' I just accepted that things had changed. I don't think about them that much now. I guess it's not better and it's not worse. (02)

> I just accept it 'cause that's how it has to be. Yeah, you eventually know you pretty much have to accept it because you can't really change it ... like, you just accept what is going on and pray and just hope everything is going to be ok. (02)

One informant explained how he is able to put things into perspective:

> My brother is really one of a kind I think. Sometimes he is just really mellow, other times he is really happy. Sometimes he can be sad. But even when things are at their worst my brother is still funny about it. Like he'll laugh a lot and make fun of me but I will laugh with him. Yeah, he's

changed and I've changed too. It makes me feel a lot better than before his injury. Because before his injury I took him for granted. (02)

Another informant reported that she couldn't remember what her life was like before her brother's brain injury and put the changes to her life into perspective in this way:

> I don't know what it would be like growing up with a brother without a brain injury or what my life might have been like ... so, I don't know what it would be like because it has always been like that ... he's just my brother. (02)

Another informant summed up how he came to the point of putting the changes into perspective and getting on with his life:

> I realized that you just have to get on with things and make the best of things. When I think about it, the extra chores ... I think was kind of good for me 'cause it taught me how to work hard .... I don't know, I've just accepted the changes ... I don't feel resentful anymore because I know he needs more than I do ... I just help him. Again, I've come to accept it.... Just that it's a lot of hard work to be there for him, to help him out as much as you can. It gets better but it's never finished. The extra work is worth it, in his recovery I guess, he can come back to kind of a normal life. I guess it's been as positive an experience as it can be, We are closer ... I think he's a better person to be around.... In some ways it's turned out good. He's different than before, but we're a lot closer. I think I know him a lot better now and I just have to learn to deal with things that he does that annoy me. (02)

Reluctant Acceptance

The action/interactional strategies of distancing by ignoring and leaving accompanied by emoting strategies often resulted in a consequence of reluctant acceptance with some lingering resentment of the changes in their lives.

> I get kind of ... I don't know if it's embarrassed ... but when we are in a restaurant and he stands up and walks around, it just kind of bugs me.... But I've learned to accept it. You can't change the way he is so you have to deal with it.... I don't know, like I baby-sit him and stuff.... Like... if I had a choice I would probably choose not to. Because I just ... I don't hate him or anything it's just ... he's just kind of difficult to take care of....

Things probably would have been a lot different for me if he hadn't had a brain injury.... We wouldn't have moved... It's just too frustrating to think about that. I guess I just have to accept it ... I can't change things. (02)

I knew that he couldn't do it so I just did it for him. It was upsetting though. But I just took it, I just did it. (02)

It's different, not the same any more at all. I just have to accept that I guess.(02)

Notations Regarding Context

As noted previously in this chapter, the context, a set of conditions which influence the action/interactional strategies, is the family, the siblings developmental stage and the sibling relationship prior to the brother's brain injury. The influence of family environment of rural versus urban identified from the demographic data was a factor that was most evident in the disruption to normal family routines. Rural parents had to travel further to spend time with the injured child in hospital and thus, were separated from the other children for longer periods. However, the influence of family environment was not specifically explored in this study. Sibling's perceptions of how their family was coping was presented as it pertained to each action/interactional strategy. The effect of the sibling's developmental stage and the previous sibling relationships were also presented with each action/interactional strategy. It is important to note the relationship between developmental age and previous sibling relationships. Siblings who were of pre-school or early school age at the time of their brother's injury characterized their relationship with their brother as one of a playmate and friend and were more likely to feel the loss of their brother as a playmate. Adolescent siblings were less likely to consider their brother as a friend prior to his brain injury and most siblings did not consider that they had a close relationship before the injury. There was no difference in siblings' experiences between those whose brother had a traumatic brain injury and those who had an acquired brain injury or the degree of the disability.

One sibling's experience did not fit within the evolving process and can be viewed as an atypical case. This sibling was very young, of preschool age, when her

brother sustained a brain injury. Her relationship with her brother and her roles within the family have developed since his injury. However, she experiences similar disruptions to family routines and realizes that her family is different than those of her friends because of her brother's brain injury. She also is going through a similar adjustment process as she deals with the impact of living with a brother who has cognitive, behavioural, and physical disabilities.

An additional noteworthy finding occurred between the first and second interviews. Following the first interview six of the informants reported that it was the first time they had discussed with anyone how their brother's brain injury had affected them. They commented that it had helped them put everything that had happened into perspective and despite being upset talking about their brother's injury, they felt much better afterwards. Three informants decided that after the first interview they it would be beneficial to share their experience with others; two used the topic for a class assignment and a third sought support from a school counselor for the first time. Thus, it would appear that being interviewed about the impact of their brother's brain injury had a therapeutic effect for these siblings.

Conclusion

In this chapter, the findings of the research study have been presented. The transactional system approach was used to present this grounded theory. The antecedent condition to the process of changing lives was presented, followed by the action/interactional strategies informants used in this process. Finally, the consequences

of the action/interactional strategies were presented, as were notations concerning the

context within which the strategies were used.

CHAPTER V

DISCUSSION

The purpose of this research was to identify, describe and propose a substantive theory of the impact of a brother's brain injury on his siblings. Siblings in this study described a process of changing lives from the time they learned about their brother's brain injury until they reached the point of deciding to get on with their lives.

In this chapter, the findings of this research regarding siblings' experience of living with a brother who has a brain injury will first be presented in light of supportive theory and current literature. Because of the small amount of literature available pertaining to the impact of a child's brain injury on his/her siblings, literature relating to siblings of children with other chronic conditions will be included in this discussion. A summary of the similarities and differences in study findings compared to previous research is provided (refer to tables 3 and 4) Second, key elements of the findings will be discussed. Following this, the implications of the findings for nursing practice, education and research will be discussed. Finally, the chapter will conclude with an examination of the strengths and limitations of this research study and summarizing statements.

Review of the Findings

For siblings in this study, changing lives has been identified as the basic social process from the time they learned of their brother's brain injury until they were able to get on with their lives. The antecedent condition, learning about the injury, led to the core

category of changing lives.

Learning About the Injury

Learning about the injury encompasses the time that siblings first heard about their brother's brain injury, as well as a period of uncertainty about his condition and recovery while he was in hospital. All but one informant reported that learning about their brother's brain injury was a very stressful experience creating fear, confusion and uncertainty. The one sibling who had no memory of the event, the youngest of the informants, was three at the time of her brother's brain injury.

Stressors can be viewed as unexpected traumatic events, brought on by factors beyond one's control. (Midlarsky & Hannah, 1989). Stress is defined as a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being (Lazarus & Folkman, 1984). Stress for children has been defined as anything that makes children "feel bad, nervous or worried" (Lewis, Seigal & Lewis, 1984, p. 117). While stress for one child is not necessarily stress for another (Rutter, 1981), the hospitalization of a child has been determined to be a stressful situation for a sibling regardless of age (Craft, Wyatt, & Sandell, 1985; Morrison, 1997; Simon, 1993; Wade & Taylor, 1996). Informants in this study reported that the sudden and unexpected injury to their brother was a very stressful event for the whole family. Stress for siblings was increased by a lack of information about their brother's injury and recovery.

Being Kept in the Dark

Informants felt like they were being kept in the dark about their brother's brain

injury, his condition and prognosis for recovery because they were given either no information or only partial information, which was not enough to understand what was happening to their brother. The need for more information was one of three themes Martinson, Gillis, Colaizzo, Freeman and Bossert (1990) found in their longitudinal study of 16 siblings of children with cancer. Other studies report similar lack of information given to siblings (Brett & Davis, 1988; Kleiber et al., 1995; Lehna, 1998; Taylor, 1980). Bluebond-Langer (1996) interviewed siblings and parents of children with cystic fibrosis and reported that parents give well siblings only the most basic information about their brother or sisters illness and their condition. However, in Sargent, Saherl, Roghmann, Mulhern, Barbariano, Carpenter, Dolgin, and Zeltzer (1995) study of 5 to 18 year old siblings of cancer patients, a lack of information about their brother's or sister's illness was not found.

The lack of information caused fear and uncertainty. Several informants said that they would not have been as scared if they had been told what was happening to their brother and whether he was going to get better. Another informant thought that her parents did not tell her about her brother's condition because they did not want to frighten her. This made her believe that the news must be very bad. Lack of communication between parents and well siblings leaves the child to wonder what is wrong and increases worry about the outcome (Bendor, 1989). An absence of discussion about the brother or sister's illness can foster an environment in which the sibling perceives the illness as too awful to talk about, leaving the sibling feeling isolated and distrustful (Bendor), and led to misinformation and misunderstanding (Chesler, Allswede and Barbarin, 1991). Three

informants were able to piece together information about their brother from listening to

parent's conversations with others, sometimes listening in on their telephone

conversations. Bluebond-Langer (1996) also reported that siblings drew conclusions

about their ill sibling's condition partly on the basis of conversations they overheard

between their parents and between their parents and health care staff.

Siblings felt ignored by health care professionals when they visited their brother in

the hospital. The majority of the informants were never included in discussions about

their brother. Taylor (1980) reported similar findings in a qualitative study of twenty-five

siblings, age seven to twelve years, of children with asthma, congenital heart disease and

cystic fibrosis. Siblings in her study described feeling peripheral to the rest of the family

on clinic visits and generally ignored by health care providers. Only one sibling in her

study had received information directly from a health care provider and that was at the

request of her mother.

Health care professionals were perceived by three siblings as being very negative

about their brother's prognosis. Presentation of the worse case scenario without providing

any possibility of a more positive outcome for their brother created great distress for these

informants and lasting feelings of anger. Siblings felt that health care professionals left

the family little room to be hopeful of a better outcome. Despite this, they refused to

accept the physician's pessimistic prognosis. Feelings of anger were reinforced over time

as they observed their brother surpassing the pessimistic predictions for his recovery. The

sibling's anger, as a consequence of pessimistic predictions by health care professionals,

would appear to be unique to these findings as no similar reports could be found in the

sibling literature.

Their brother's brain injury was the event that the twelve siblings in this study attributed to their changing lives. This interpretation is consistent with the family systems concept that siblings are part of a subsystem of the larger family system and all systems are viewed as inter-connected. Thus, a change in one family member affects all family members.

<u>Realizing Life is Different</u>

The life of a child is altered in a significant way by the occurrence of a critical life event (Dunn, 1984). Following their brother's brain injury siblings began to realize that their lives were different and became aware of the loss of the brother they had known. Rosenthal and Muir (1983) explain that parents experience what some have called partial death: their child is alive but is not the child they knew before the injury. Thus, sibling loss, though usually related to the death of a sibling, can be expanded to include the loss of a sibling through chronic illness or disability (Cowles & Rodgers, 1991; Pollock, 1986). Each sibling relationship is often unique, a connection that is not replicated in any other relationship (Gibbons, 1992). The impact of sibling loss, from whatever cause, can have devastating effects.

Informants who were very emotional, crying or choking back tears during interviews were those whose brother's brain injury had occurred at least five years previously. Their ages and the reported severity of their brother's brain injury did not appear to affect their degree of distress when talking about the impact of their brother's brain injury on their own and their families lives. Brooks, et al. (1986) study on the

impact of brain injury from the viewpoint of relatives five years after the injury, found a pattern of increasing stress and strain compared to that reported at one year post-injury. Other researchers have reported similar findings (Breslau & Prabucki, 1987; Orsillo et al., 1993). The observation of more distress in those siblings who had lived with the effects of their brother's injury for a longer period of time may be explained by these previous findings. As well, the severity of the brain injury has not been found to be related to sibling's level of distress (Orsillo et al., 1993; Wade & Taylor, 1996).

Family Systems Theory offers an additional explanation of the distress of these siblings. Friedman (1992) explains that Family Systems Theory suggests that changes within a family system disrupt its homeostasis causing stress and discomfort, and when the change is complete and homeostasis is restored within the family, the distress should resolve. However, in families who have a brain injured member, change is an ongoing process (Frank et al., 1994). Thus, based on Family Systems Theory homeostasis is not achieved as siblings continue to experience the changes in their lives.

Disruption to Normal Routines

Disruptions to the normal routines of informants' lives was the first indication that their lives had changed. This finding is supported by several previous studies of siblings of children with chronic disease (Bendor, 1990; Chesler et al., 1991; Chesler & Barbarin, 1987; Gallo et al., 1991; Wade & Taylor, 1996). Reports of changes in family routines have included lack of parental presence at home; disruption of individual and family routines such as chores, meals and bedtime rituals; and sibling's play patterns, causing anxiety and uncertainty. Frequent visits to the hospital caused disruption to their lives.

Some siblings in this study experienced uncertainty as a result of not knowing whether they were expected to continue with normal routines of homework and team sports, or if they were expected to forego these activities to visit their brother.

Loss of Time with Parents

The injured child's hospitalization leaves well siblings separated from their parents, especially their mothers, often for the first time in their lives. (Bluebond-Langer, 1996). Many are cared for by relatives and friends. They may see their mothers only briefly, if at all, during the sibling's initial hospitalization. Walker (1993) explained that when parents are unable to attend to the needs of the well siblings, the siblings experience the "functional" loss of the parent. In this study, parents, and especially mothers, had less time for informants as they spent most of their time at the hospital with the injured brother. For siblings from rural areas this loss was even greater, as mothers spent weeks at a time away from home in order to be with the injured child. Several siblings in this study described a permanent and significant decrease in the time they were able to spend with their parents because of the continuing stress and time commitment of caring for their brother.

Loss of a Playmate

Siblings, especially in early childhood, have close daily contact as they interact at home (Cicirelli, 1995), and are frequently each other's closest friend. All of the younger informants in this study, as well as older siblings from rural families, described losing their brother as a playmate. Siblings from rural homes reported spending more time with their brother before his injury, even in middle childhood, than did the older urban

siblings. Thus, it is not surprising that older siblings from rural homes also reported that they had lost their main playmate after their brother's injury. Their loss continued after their brother came home from the hospital because he could not do things he could before his injury, he disrupted their play with friends, and he was often uncooperative.

Loss of Time with Friends

Initially, less time for friends was as a result of the immediate disruption to their normal routines. However, for some siblings, additional responsibilities, choosing to spend more time with their brother after he came home, and a lack of understanding from friends, resulted in spending less time with friends for up to a year or longer. Less time for friends has been reported in other studies as resulting in social isolation (Breslau & Prabucki, 1987; Brett, 1988; Ross- Alaolmolki, Heinzer, Howard, & Marszal, 1995; Taylor, 1980). Breslau and Prabucki point out that social isolation may be of particular concern in childhood and adolescence, when interactions with peers form the context for learning social skills and patterns of interpersonal relationships. Social isolation was not perceived by the majority of informants in this study. Even those siblings whose activities outside of the family were greatly reduced following their brother's brain injury denied that this was a long-term problem and felt that they had sufficient contact with friends and peers. One sibling, however, did report that he was a "loner" and related this to the changes in his interactions with others following his brother's brain injury.

Adjustment of Family Activities

The adjustment of family activities, as a negative impact on their lives, was emphasized by siblings who were younger at the time of their brother's injury. Older

informants commented on positive changes to family activities such as spending more time together. This finding might be explained by the difference in siblings dependence on family activities depending on their age. Older siblings are more likely to have had more independence and support from activities outside the home that could buffer the effects of any changes to family activities to accommodate their brother. Younger children, by contrast, are much more dependent on the family for activities and support. The adjustment of family activities, as a major change for siblings of children with chronic illnesses, has been reported by other researchers (Crnic & Leconte, 1986; Derouin & Jesse, 1996; Sargent et al., 1995).

Becoming More Responsible

Becoming more responsible meant taking on added responsibilities around the house as well as feeling the need to act more responsibly. Half of the informants reported having additional responsibilities which they assumed willingly and viewed them as having a positive impact on their lives. For two siblings the added responsibilities they were expected to assume were a source of frustration and stress. Becoming more responsible for looking out for their brother and acting more responsibly in their own activities to avoid getting hurt were two ways siblings described acting more responsibly. Having to assume added responsibilities has been reported as having both positive (Gallo et al., 1992; Menke, 1987) and negative impacts (Gamble & McHale, 1989; Orsillo et al., 1993; Stonemann et al., 1989) for siblings with a chronically ill brother or sister.

Becoming Re-acquainted

One aspect of realizing that their lives were different was becoming aware that

their brother was no longer the person he was before his brain injury. Some of these changes, such as becoming more outgoing than before his injury, were viewed as positive by older informants. Younger siblings were upset because their brother wasn't as nice to them as he had been before his brain injury. Physical changes in their brother meant that he was no longer able to participate in the same way in their activities, he looked different than other children, and he had different interests than before his injury. Siblings recognized that their brother had more difficulty learning new things and could not always understand what was happening in interactions with others. Changes in behaviour were often frustrating, embarrassing, and even frightening. Personality, obvious physical changes and behavioural changes were the most difficult for the younger siblings to deal with, while cognitive and behavioral changes were more upsetting for older siblings. Another aspect that was difficult for older informants was not knowing what to expect from their brother.

Prior studies of families of individuals with brain injuries have found that cognitive and behavioural impairments were the most difficult to deal with (Gill, 1998; Florian et al., 1989; Kreutzer et al., 1992; Livingston & Brooks, 1988; Stebbins & Leung, 1998)). Therefore, the findings in this study that personality, cognitive and behavioural changes were most upsetting is consistent with previous literature. The recognition that they must become re-acquainted with their brother is consistent with Family Systems Theory that views changes as circular causality. That is, each individual's behavior has an effect on and influences the other (Wright & Leahey, 1994). The changes in their brother required changes to their own lives to accommodate their "new" brother. As one sibling

explained, " Yeah, it was weird, like a piece of you had been taken away and you have to learn this new piece, all different."

Changing Roles

At the same time siblings were becoming re-acquainted with their brother, they often experienced changes to their roles within the family. Members of a family occupy a specific position or status, and for each position, role prescriptions specify appropriate behaviors and regulate relationships within family members daily living. (Chesler, Allswede & Barbarin, 1991). Family roles are reciprocal in that the roles of each family member are related directly to roles played by each other family members (Friedman, 1992; Williams, Lorenzo, & Borja, 1993). The demands of a chronically ill child causes families to cope with the situation by a reorganization of family roles (Williams, 1997).

Similar to Menke's (1987) findings, siblings in this study assumed a protective role as they realized that their brother had problems in interpersonal relationships, had physical limitations, and difficulties in school that might impact on his ability to attain a "good" education. Two informants accepted that they might have to continue in this role indefinitely, and they discussed supporting their brother in the future if he was not able to obtain a good education. Four of the older siblings took on a caregiver role, assisting their parents in physically caring for their brother as he began his recovery at home. Three of the four were sisters, two younger and one older than their brother. Willer, Allen, Durnan, & Ferry, (1990) also reported that siblings frequently took on the role of assistant parents. While only two informants specifically reported taking on the role of their brother's primary coach, others also pitched in to assist their parents in helping their brother with

his school work. One of the youngest informants assumed the task of interpreting what her brother was trying to say to his friends, and parents and an older informant routinely helped his brother with homework. Rothery (1987) also reported siblings acting as teachers for their disabled siblings. Three of the four younger siblings assumed the role of eldest in the family. Assuming the role of their older brother was sometimes uncomfortable for siblings when their brother, because he could not understand, resented them assuming his place in the family. Chesler et al. (1991) found that in some families, a shift in sibling hierarchy when the ill child was treated as the "youngest" displacing the younger siblings as the focus of parental care, caused resentment, frustration, and disappointment. Younger siblings in this study did not feel displaced, on the contrary they viewed assuming the role of eldest in the family provided them with an opportunity to contribute to the family's adjustment to their brother's injury.

Changing Relationships

As siblings became re-acquainted with their brother and experienced changing roles within the family, relationships with their brother, other family members and friends also changed. Eight siblings developed closer relationships with their brother, while the relationship of four siblings with their brother became more strained. Those who experienced a closer relationship became better friends, often making up for the friends their brother had lost following his injury. They made more time for their brother, made an effort to include him in their activities, and willingly adjusted their lives to accommodate their brother's limitations. A more strained relationship was attributed to having to be more careful in their interactions and increased fighting with their brother.

One sibling resented what he perceived to be his brother using his brain injury to "get out of" tasks and ignore family rules. Another sibling expressed ambivalent feelings toward his brother.

Closer family relationships showed a correlation with a closer sibling relationship. Closer family relationships resulted from spending more time together as they realized how uncertain life can be, improved family communication, and working together to find ways to cope with the impact of the brother's brain injury on their lives. Two of the four siblings who had a strained relationship with their brother had neither a closer nor more strained relationship with their parents. However, one sibling experienced a more strained relationship with his parents as a result of their treatment of his brother. One informant who spoke of her family as "just us four; Mom, Dad, Jim and me. Not grandma or grandpa...", described a more strained relationship with the extended family. This description suggests that this family closed itself off from any assistance from their extended family. In systems theory, systems are arbitrarily defined by their boundaries. In family systems, the boundary must be both permeable and limiting. If the family boundary is too permeable, the system loses its identity and integrity and therefore does not allow the family to use its own resources in decision-making. However, if it is too closed or impermeable, input or interaction with the outside world is shut off (Wright & Leahey, 1994).

Reports of closer or strained relationships demonstrated no consistency in relation to the siblings age or their position in the sibling dyad. Closer relationships were experienced by siblings both younger and older in age than their brother and by siblings

who had been less than ten years of age, and those who were in their mid to late teens at the time of their brother's injury. These findings do not support earlier findings that sibling age has a correlation to the stress experienced and the quality of the sibling relationship. Pouts (as cited in Crnic & Leconte, 1986) reports that the younger the age of the sibling and their disabled brother or sister the less stressful the sibling relationship. Positive relationships have also been associated with siblings being younger than the disabled child (Simeonsson & McHale, 1981), others have reported that young male siblings who are close in age to the disabled child experience the greatest stress (Conolay & Sheridan, 1996). However, consistent with the findings in this study, previous research has found that chronic disease may threaten the integrity of the sibling relationship, both directly and indirectly (Boer, 1990; Trahad, 1986). Directly, the opportunities to interact with the disabled brother or sister may be reduced, as the disabled child is physically less able to keep up with the well sibling (Trahd). Relationships may be affected less directly when siblings perceive that they are treated differently, that they are more likely to have to follow family rules while excuses are made for their brother or sister (Boer).

Informants found that relationships with some friends became very close, while they chose to distance themselves from others. Chesler et al. (1991) reported that siblings may find it difficult to explain their brother's or sister's illness. The siblings who often have to defend the sick child's appearance or inappropriate behavior from the ridicule of friends, frequently withdraw from these friends. Two siblings in this study were upset by the reactions and negative behaviour of their friends towards their brother and chose to distance themselves from those friends.

<u>Adjusting to the Changes</u>

Having a disabled brother or sister is a significant source of stress across the age span that requires ongoing adjustment/adaptation by siblings. Sibling coping and adaptation is a transactional rather than a fixed process (Crnic & Leconte, 1986), that is influenced by the environment, the personality, and the situation (Folkman & Lazarus, 1988; Lazarus & Folkman, 1984). Lazarus and Folkman stress that coping responses are based on the meaning or appraisal which an individual ascribes to an event. As well, two broad dimensions based on the intended functions of coping are identified. Problem-focused strategies are aimed at changing the problematic situation, while emotion-focused strategies are aimed at managing or reducing the emotional distress.

As the siblings in this study realized that their lives were different following their brother's brain injury, they employed various coping strategies to adjust to the changes. Strategies often changed over time and several strategies were frequently used at once. Informants used four adjustment strategies: distancing themselves from an uncomfortable or upsetting situation; seeking support from various sources to cope with the changes to their lives; altruistic helping; and, emoting (reacting emotionally by crying or getting angry).

The Lazarus and Folkman (1984) framework of stress, coping and adjustment places great emphasis on cognitive processes in determining what is experienced as stressful, and how one copes with a stressful event. Two important factors which influenced young sibling's appraisal of the stress of their brother's brain injury and subsequent coping strategies were the sibling's immature (but developing) cognitive

abilities, and dependence upon their parents for information. These factors contributed to siblings poor understanding of brain injury and its effect on their brother.

Distancing

Distancing describes efforts to detach oneself. In distancing, the difficult situation is acknowledged but the person does not want to deal with its emotional significance (Folkman & Lazarus, 1988). In this study distancing was the initial strategy used by the majority of informants. Distancing was often replaced by more problem-solving strategies as siblings became better acquainted with their brother, and as they experienced more positive changes in their brother's behaviour over time. However, for younger siblings and two older brothers, distancing behaviours such as ignoring their brother and going away, continued to be their main way of coping. Ryan (1989) in a study of children ages 8 to 12, also found that following a stressor, distancing behaviours such as isolating behaviours and avoidant behaviours were common. Ryan defines isolating behaviours as those "behaviors that serve to separate an individual from the presence of others" (p.116). Avoidant behaviours are "behaviors other than isolating behaviors that are deliberate attempts to avoid dealing with the stressor" (p.116). Ryan's isolating behaviours are similar to informant's reports of "going to my room" and "locking myself in the bathroom." Avoidant behaviours in this study were "ignoring him" and "not paying any attention to what they say."

Keeping feelings to self and not asking questions were other distancing strategies used by siblings in this study. Younger siblings reported that they had many questions that they would have liked to ask their parents more often than older siblings. The most

frequent reason given for not seeking answers to their questions was fear of the answer and not knowing how to phrase the questions. Older siblings did not discuss their feelings and questions because they either could not talk to their parents or they did not want to add to their parent's grief. Attig (1997) states that when children experience loss, such as the loss of their brother after his brain injury, they have many questions. When parents do not explain what is happening, and only talk about the injury when they think that they can not hear, it seems like no one wants to answer their questions, so they keep them to themselves.

Lazarus and Folkman (1984) suggest that distancing should not interfere with successful problem-solving and that distancing may be adaptive in situations where nothing can be done. Roth and Cohen (1986) further suggest that in uncontrollable stressful situations avoidance may provide the person time to mobilize more active problem-solving or positive cognitive reappraisal. This appears to be the case for many siblings in this study.

Seeking Support

Seeking support, as an adjustment strategy, was the second strategy used by ten of the siblings in this study; seven turned to their parents or other family members, two had a supportive friend, and two received help from a teacher or psychologist. Seeking support from family members was used by the majority of adolescent siblings as they tried to cope with the changes to their lives. Many siblings used more than one source of support and only one found that a friend provided more support than their family. All of the younger siblings turned to their parents for assistance when they had encounters with

their brother that they were unable to cope with. This last finding may be explained by the differences in siblings' developmental level that may limit their choice of coping strategies. Kopp (1992) suggests that very young children do not have the physical and cognitive resources to deal with a source of stress without assistance. While older children, whose motor, cognitive, and material resources are greater, often can leave a stressful situation, physically master the stressor, or master the necessary cognitive and communication resources for coping with stressful situations (Altshuler & Ruble, 1989; Band & Weisz, 1988; Ryan, 1989). Maternal support, also associated with children's use of avoidant strategies in uncontrollable situations, is viewed as an appropriate strategy (Eisenberg, Faber, & Guthrie, 1997). Wolchuk and Sandler (1997) propose that a child's understanding is a factor in their stress-related responses and coping. The understanding of another's intentions is important for developing a plan of action. In this study negative behaviour toward the sibling caused greater distress for younger siblings than for older siblings, as they appraised their brother's negative behaviour as a personal attack on them, rather than a consequence of their brother's brain injury.

Three siblings were supported by their faith in God to accept the changes that they experienced in their lives. Turning to faith in God as a coping strategy has been reported by other researchers (Britt,1995; Pettle & Britten, 1995). Pettle and Britten found that adolescents with strong religious backgrounds may find their faith a source of comfort and strength when coping with stressful situations. Britt reported that the more threatening children appraised a situation to be, the more likely they were to use religion to cope.

Altruistic Helping

Altruistic behaviour is, by definition, a form of behaviour intended to help others and not expected to bring extrinsic rewards (Midlarsky & Hannah, 1989). Altruistically motivated, moderate levels of helping, serve as an active form of coping and are associated with lower instances of emotional problems in siblings of the handicapped (Ferrari, 1987; McKeever, 1983).

Siblings in this study who chose altruistic helping as a coping strategy received similar benefits. Each sibling found different, often age appropriate ways to help that showed concern and empathy for their brother. Altruistic helping led to an improved relationship with their brother and a better understanding of the difficulties he faced as a result of his brain injury. Thus, altruistic helping was a productive and successful coping strategy, making it easier to cope with the changes to their own lives and the changes in their brother.

Emoting

Emoting is a form of emotion-focused coping. Crying, as a reaction to their changing lives, was reported by sisters more often than brothers, while becoming angry was a more common reaction in brothers. Other researchers have supported this gender difference in emotion-focused coping (McCubbin & Patterson, 1983; Ryan, 1989; Sorensen, 1990; Spirato Stark & Williams, 1988). Girls were found to consistently use emotional expression as a coping strategy more often than boys. In contrast no sex differences were observed in several previous studies (Altshuler & Ruble, 1987; Walker, 1988). The younger the sibling in this study the more emoting strategies were used as the

main way of coping. Developmentally, young children have not yet achieved cognitive skills required to cope with stressors, as cognitive mastery is not usually present before age eight.(Piaget, 1960; Sargent et al., 1995).

In summary, the findings of the adjustment phase of the process of changing lives can be understood by examining coping and development as conceptualized in the McGill Model of Nursing. The McGill Model of Nursing, developed from a family systems perspective, views coping as one dimension of health. Coping is a function of problem solving. Individuals cope by "identifying the problem, finding alternative actions, and evaluating these alternatives" (Gottlieb & Rowat, 1987, p.54). The second dimension of health is development. Development is directed at setting goals and utilizes the resources of the individual, family and community (Warner, 1981). Coping and development evolve over time,are interconnected and are learned within the context of the family (Gotlieb & Rowat). In this study, a more positive consequence was the result of more effective problem solving, the positive resource of good family communication and a positive reappraisal of their changing lives. Gill (1998) in her study of siblings of adolescents with TBI reports that Family Systems Theory does not address how family members learn new behaviors to deal with a change within the family. However, by utilizing the McGill nursing model to understand sibling coping actions as problem solving and developing, the manner in which siblings in this study learned new behaviours to cope with the changes to their lives can be understood.

Distancing strategies were frequently the initial strategies employed by siblings as they adjusted to the changes in their lives. For a few siblings distancing remained their

only strategy. For the majority of siblings however, distancing strategies were replaced or added to by support seeking and often altruistic helping. Emoting strategies were also reported to be used in conjunction with distancing and seeking support. The eventual consequence of their changing lives was reaching a point of getting on with their lives, either by putting the changes into perspective or by a reluctant acceptance of the changes.

Getting on with Life

Getting on with their lives was the third phase in the process of changing lives following their brother's brain injury. As siblings moved through the previous two phases of realizing life is different and sought ways to adjust, they reported reaching a point where they could either put the changes to their family and themselves into some perspective or they reluctantly accepted the changes. Not all siblings in this study had progressed to this phase. Three siblings whose brother had sustained a brain injury within the past two to three years were still going through the first two phases. Of the eight remaining siblings, five reported being able to put the changes into perspective, while three had reluctantly accepted that their lives had changed.

This phase is similar to the reappraisal stage in the stress, coping and adjustment framework of Lazarus and Folkman (1984). Siblings who were able to put things into perspective still realized that the changes to their lives had not ended but would be an ongoing process. However, they were able to acknowledge that they had experienced positive changes as well as negative ones and the majority experienced more positives than negatives. As a result of this positive reappraisal these siblings had developed closer

relationships with their brother and other family members.

Negative reappraisal of their situation produced a reluctant acceptance that was was expressed in terms of ambivalence toward their brother and an absence of anything positive as a result of their brother's injury. These siblings were not happy with many of the changes to their lives and expressed a belief that they could do nothing to improve these negative changes. This reluctant acceptance also appears to be similar to the resignation that Perez (1997) found to be common in adolescents in response to their own chronic illness.

<div align="center">Key Elements of the Findings</div>

Two key elements can be identified from the data generated in this study. First is the anger that was experienced by some siblings as a result of the pessimistic prognosis presented to families by health care professionals. Second is the relationship of the quality and amount of information that siblings received which influenced the process of their changing lives.

Anger

Anger was a reaction that siblings experienced as a result of what they perceived to be the pessimistic predictions by health care professionals about their brother's recovery. The anger they felt intensified over time as they observed their brothers surpassing the negative predictions. One informant explained it this way:

> ...it was so wrong because he walks and stuff now. It still makes me pretty mad cause it was all negative .... and it was wrong.

An explanation for this anger may be that these siblings believed that the health care

professionals left no room for hope that their brother would recover. Hope was something that they desperately wanted to have, and the realization over time that the situation was not as hopeless as they were led to believe reinforced their anger. To better understand their feelings, it is important to explore the concept of hope and its contribution to the process of coping and adaptation in stressful situations..

Hope is an elusive concept which has been difficult to describe. Hope has been identified as an important component for coping with stress in life-threatening situations (Herth, 1989). Hope is seen as important for coping in being a resource for coping (Owen, 1989; McGee, 1984), a coping task (Miller, 1992), a result of successful coping (Scanlon, 1989) and a strategy for coping (Rustøen, 1995). Hope gives strength to solve problems and can enable individuals to handle losses, tragedies, loneliness and suffering (Nowotny, 1989; Scanlon, 1989). Rustøen states that strong hope gives strength and courage to persevere in dealing with difficult situations. Loss of hope can result in several negative consequences: apathy, inactivity, meaninglessness, and hopelessness (Fromm as cited in Benzein & Saveman , 1997).

There are many definitions of hope. Rustøen (1995) states hope is a "six-dimensional, dynamic attribute of the person which orients to the future, includes active involvement by the individual, comes from within, is possible, relates to or involves others or a higher being, and relates to meaningful outcomes to the individual." (p.89). (Stephenson, 1991) defines hope as "a process of anticipation that involves the interaction of thinking, acting, feeling, and relating, and is directed toward a future fulfillment that is personally meaningful" (p. 1459). Morse and Dobernick (1995) define hope as

a response to a threat that results in the setting of a desired goal; the awareness of the cost of not achieving that goal; the planning to make the goal a reality; the assessment, selection, and use of all internal and external resources and supports that will assist in achieving the goal; and the working reevaluation and revision of the plan while enduring, working, and striving to reach the desired goal (p. 284).

Implicit in these definitions is the idea that hope involves an active process. Hope involves an active interaction of a person's thoughts, feelings, actions and relationships (Hickey, 1986). When an individual wants to be hopeful they search for clues to provide the grounding for hope. This grounding can be based on realistic or unrealistic expectations, but as long as the individual believes that a foundation is present upon which hope rests assurance will be felt (Wright & Shantz, 1968). Hickey (1986) proposes that false hope may serve a useful purpose for a period of time. It may give the family the necessary time for assimilating the resources and coping skills so that they can deal realistically with the health crisis. Kaplan (1983) emphasizes that health care professional should communicate hope and confidence.

The opposite of hope is hopelessness. The term 'hopeless' means providing no hope, beyond optimism, without hope, and the term 'hopelessness' means the condition or state of being without hope (Webster's College Dictionary, 1995). Lazarus (1993) defined hopelessness as "inaction in the face of threat" which places the hopeless in a passive, inactive state.

Thus, sibling anger can be understood to be a positive reaction to the negative predictions of health care professionals. Siblings focused their anger at the health care

professionals who left them feeling hopeless when they needed to maintain hope to give them the strength and courage to cope with their brother's brain injury. Siblings wanted to be able to believe in the possibility of recovery for their brother and did not want to believe that the situation was hopeless. Their anger was reinforced, as their brothers proved the negative predictions wrong and they reflected on what they perceived as the unnecessary distress that the negative predictions had caused.

Relationship of Information and the Consequence of their Changing Lives

The second key finding is the strong relationship between the quality and quantity of information that siblings received, their ability to discuss their feelings and ask questions within the family, and the consequence of their changing lives. This relationship can be shown as a continuum (Figure 2).

Previous studies have identified that children who cope and adjust in a more positive manner to a brother's or sister's chronic illness are those who are provided with complete age appropriate information about various aspects of the illness, have questions answered and are permitted to express their emotional responses (Gallo et al., 1992; Pettle & Britten, 1995; Taylor, 1980). Effective communication has been shown to be an essential element in facilitating individual and family coping with childhood chronic illness. Communication is not just providing facts but the creation of a climate that encourages the expression of feelings (Davies, 1999).

Since all siblings in this study experienced distressing disruptions to their normal routines following their brother's brain injury, siblings who experienced a more positive journey through the process of their changing lives had acquired sufficient information

about their brother's injury and the effects of the injury which enabled them to better understand and accept the changes in their brother. They also reported good or improved family communication. These siblings developed closer relationships with their brother, employed more positive than negative coping strategies and were eventually able to put their changing lives into perspective. Siblings who acquired little information had a poor understanding of the effects of their brother's brain injury or the permanence of some of his disabilities. For these siblings their journey through the process of their changing lives was frustrating and unnecessarily stressful. They had more ambivalent feelings toward their brother and/or a more strained relationship, often a more strained relationship with other family members, employed more negative coping strategies and eventually came to a reluctant acceptance of their changing lives. Lazarus' (1993) stress and coping model places great emphasis on the role of cognitive processes in determining what is stressful, and how one copes with a stressful event. (Lazarus & Folkman, 1984). Thus, siblings who did not understand the effects of their brother's brain injury were unable to employ appropriate strategies to cope positively with the stresses that they experienced. Those siblings who reported more positive experiences reported ongoing family communication and a continual search for information which would enable them to cope with new and changing stressors. The three siblings who experienced more negative outcomes reported that once their brother came home family members did not discuss their brother's injury, that they "tried to put it behind them."

Previous studies report several reasons why children do not have sufficient information about a brother's or sister's illness. Children may be totally dependent on

their families for information (Davies,1999), and parents often feel that they are

protecting siblings, especially young siblings, by not discussing the illness (Brett &

Davies, 1988; Kleiber, Montgomery & Craft-Rosenberg, 1995; Taylor, 1980). Parents

sometimes withhold information that they feel is too "scary" or negative (Kleiber et al.).

Davies states that it appears that some parents underestimate their children's ability to

understand and their desire to be given information about their brother's or sister's

illness. Lack of discussion about the injury or the stress of changes in the injured child

can mean not only no further acquisition of information, but also no further search for

information. By the time that siblings are older and ready for more information, parents

do not offer it, and siblings do not ask (Bluebond-Langer, 1996).

**Figure 2. Relationship Between Information and Family Communication
and the Consequence of Changing Lives**

Little information   Complete information
Poor family communication   Good family communication

- _____ +

Reluctant   Putting changes into
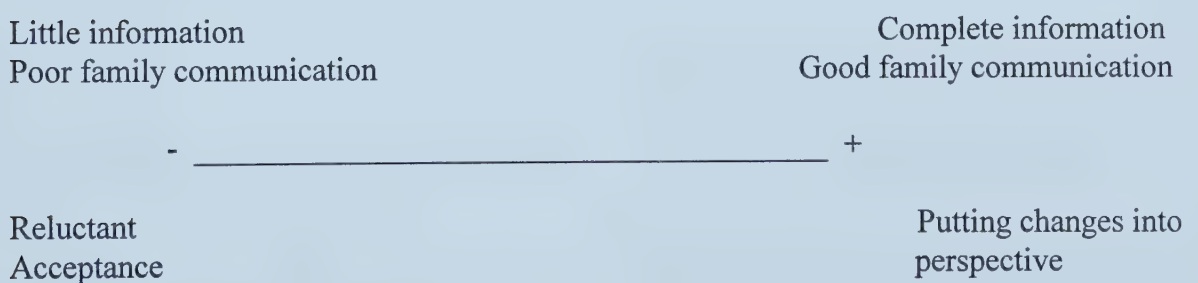Acceptance   perspective

Table 3

Summary of the Similarities of This Study's Findings with Previous Research

STUDY FINDINGS	OTHER RESEARCH STUDIES
Hospitalization of a child is stressful for siblings regardless of siblings age	Craft et al., 1985; Morrison, 1997; Wade & Taylor, 1996.
Most siblings reported insufficient information to understand what was happening to their brother	Martinson et al., 1990; Brett & Davies, 1988; Kleiber et al., 1995; Lehna, 1998; Taylor, 1980.
Siblings reported feeling ignored by health care professionals	Taylor, 1980
Degree of stress was not related to siblings age or severity of brother's brain injury	Allen et al., 1994; Orsillo et al., 1993; Wade & Taylor, 1996
Siblings who lived with their brain injured brother five years or more reported greater levels of stress	Breslau & Prabucki, 1987; Brooks et al., 1986; Frank et al., 1994; Orsillo et al., 1993
Disruption to normal routines	Bendor, 1990; Chesler et al., 1991; Gallo et al., 1991; Wade & Taylor, 1996
Loss of time with parents	Bluebond-Langer, 1996; Walker, 1993
Loss of time with friends	Breslau & Prabucki, 1987; Brett, 1988; Ross-Alaolmolki et al., 1995; Taylor, 1980
Changes in their brother viewed as the loss of the brother they once knew	Cowles & Rodgers, 1991; Pollock, 1986
Adjustment of family activities	Crnic & Leconte, 1986; Derouin & Jesse, 1996; Sargent et al., 1995
Assuming added responsibilities: with both positive and negative outcomes	Gallo et al., 1992; Gamble & McHale, 1989; Menke, 1987; Orsillo et al., 1993; Stonemann et al., 1989
Changes in cognitive, emotional and behavioural impairments most difficult to deal with	Gill, 1998; Florian et al., 1989; Kreutzer et al., 1992; Livingston & Brooks, 1988; Stebbins & Leung, 1998
Changes in roles	Menke, 1987; Jessop & Stein, 1989; Rothery, 1987; Williams, 1997; Willer et al., 1990
Closer family relationships	Havermann & Eiser, 1994; McHale et al., 1986
Sibling use of distancing strategies	Attig, 1997; Ryan, 1989
Siblings seeking support	Britt, 1995; Eisenberg et al., 1997; Pettle &

STUDY FINDINGS	OTHER RESEARCH STUDIES
	Britten, 1995
Siblings use of altruistic helping	Ferrari, 1984; McKeever, 1983; Midlarsky & Hannah, 1989
Emoting, crying most often reported by sisters, brothers reported getting angry	Patterson & McCubbin, 1983; Ryan, 1989; Sorensen, 1990; Spirato et al., 1988
Emotion-focused strategies main strategy of younger siblings	Sargent et al., 1995; Piaget, 1960
Significant, lasting changes to sibling's lives	Gill, 1998

Table 4

Summary of the Differences in this Study's Findings with Previous Research

STUDY FINDINGS	PREVIOUS RESEARCH
Anger directed at health care professionals in response to the presentation of a worse-case senario of the injured child's prognosis without providing the possibility of a more positive outcome	Not found in previous sibling studies
No perception of social isolation as a result of spending more time with their family and injured brother	Social isolation of siblings reported by Breslau & Prabucki, 1987; Brett, 1988; Ross-Alaolmoki et al., 1995; Taylor, 1980
Younger siblings viewed assuming the elder sibling role positively as an opportunity to assist family adjustment	Chesler et al., 1991 reported that the displacement of younger siblings as the focus of parental care caused resentment and frustration
Changes in sibling relationships demonstrated no consistency in relation to sibling age or their position in the sibling dyad	Report that the younger the sibling and the ill child the less stressful the sibling relationship, Crnic & Leconte, 1986; positive relationship when sibling younger than disabled child, Simeonsson & McHale, 1981; young male siblings closer in age to ill child report greatest stress, Conolay & Sheridan, 1996

Implications For Nursing

Findings from this research study have implications for nursing in the areas of practice, education and further research.

Nursing Practice

Nurses have unique opportunities to promote positive adaptation for families experiencing the stress of a child's brain injury. It is important that a family systems perspective guide nurses as they assess the strengths, vulnerabilities, and coping abilities of all family members. Nurses first need to recognize and deal with the stressful hospitalization as it is perceived by each family member. Most siblings in this study found health care professionals to be of little support during their brother's hospitalization. Siblings reported being ignored, seldom included in discussions about their brother, and hearing only negative predictions for his recovery, which added to their distress and anxiety. This also created, for some siblings, a reluctance to visit their brother in hospital.

Siblings need to be acknowledged as important members of the family who have a significant role in their brother's or sister's recovery. Nurses need to plan conferences to include all family members. Family conferences can be a means to facilitate family communication and encourage expression of sibling concerns, feelings, and questions. Siblings need to know what is happening, what to expect of their brother at each stage of his recovery, and how to cope. A better understanding of the effects of brain injury on their brother may help siblings avoid misunderstandings about the effects of the injury and, therefore, improve the potential for the development of closer relationships. Many

siblings avoided asking questions, despite their desire for information, simply because they were too afraid of the answers, or did not want to add to their parent's distress. Parents may feel uncomfortable or uncertain as to what they should tell their well children. Nurses can provide education and assist parents to decide what information to give to siblings. Siblings need age-appropriate, honest and up-to-date explanations about what is happening to their injured brother or sister. Information was shown to be a key component of sibling coping strategies. Regardless of their age siblings want to feel as though they are included in what is happening. Siblings need to be able to maintain hope for their brother's recovery. Findings from this study show the negative effects on siblings who perceived that health care professionals left them with no hope for their brother's recovery. Nurses and all health care professionals should be careful to leave room for hope when any chance of recovery is possible.

Nurses can facilitate ways for siblings to maintain contact with their injured brother or sister and participate in their care. Distance was cited as a barrier for several siblings to visit the hospital. Telephone calls, letters, and pictures showing the injured brother's or sister's progress may be helpful in maintaining this contact when frequent visits are not possible. Previous research, as well as findings from this study, have shown the benefit of siblings being involved in the care of their brother in the development of closer sibling relationships. Davies (1999) states that children who are allowed to choose their own ways of helping their brother or sister, will often do so willingly and not be resentful of the extra expectations placed on them.

Nurses should educate parents about the importance of providing as much time

and attention as possible to siblings as well as the injured child. Nurses can provide anticipatory guidance regarding siblings' normal reactions to and concerns about the changes to their lives, the importance of encouraging siblings to express their feelings both positive and negative, and the importance of updating information for siblings as their level of comprehension increases and circumstances change over an extended period of time. Nurses can help the family to focus on some of the positive outcomes identified in this and other studies such as closer relationships and improved family communication.

Nurses can communicate to siblings that negative emotions are normal and expected to some extent. Siblings in this study found that being able to talk about their experiences and learning that others had spoken of similar experiences was very helpful in putting the changes to their lives into perspective. Nurses can develop support groups where siblings can acquire new knowledge and feel comfortable in sharing experiences with other brothers and sisters in similar situations.

Nursing Education

Nurses caring for children who have suffered a brain injury must have a thorough understanding of family systems theory to ensure that the focus of care is on all members of the family, not just the injured child. Nurses need to understand the special importance of the sibling relationship and how best to foster positive continuation of that relationship when one sibling has a brain injury. Knowledge of the long term effects of brain injury on all members of the family and children's normal coping and adjustment strategies will enable nurses to provide anticipatory guidance to minimize the potential negative effects of a child's brain injury on the family unit. Nurses need to understand that the impact of

living with a child with a brain injury requires ongoing coping and adaptation to change for an indefinite period of time.

Assessment and communication skills need to be developed ito enable nurses to assist families through this very stressful period. Assessment skills should focus on the psychosocial needs of each member of the family. Each family member experiences stressful situations from their own perspective. Thus, what is stressful for one may not be the same for other family members. Communication skills would include developmentally appropriate communicating with children and the ability to develop a trusting relationship in which siblings would feel comfortable expressing their emotions and asking questions.

Nursing Research

The findings of this study have implications for further research. The sample was one of convienence, was relatively small, and included a range of developmental stages (ages 7 to 21 years) and years since the injury occured (1. 5 to 10 years). Therefore, longitudinal research in this area with a larger sample is needed to examine the siblings' experiences at different developmental stages and to determine if their perceptions of living with their brother or sister change over a longer period of time. The brain injured children in the sample families were all boys, which coincides with current statistics showing that boys are more likely to sustain brain injuries than are girls (Goldstein & Levine, 1987). However, further research with siblings of sisters who have sustained a brain injury is needed to discover if the sibling experience is different when the injured child is a sister.

This study showed that information about their brother's brain injury and the effects of the injury for their brother, significantly influenced the process of their changing lives. Additional study of factors that lead to more positive experiences for siblings as they experience the process of changing lives would assist health care professionals to plan and evaluate interventions to promote more positive adaptation for siblings. A second finding, unique to this study, regarding the angry reaction of some informants to health care professional's negative predictions for their brother's recovery needs to be further studied to validate this finding.

Strengths and Limitations of the Study

Strengths

A strength of this study was obtaining sibling's perceptions of their experiences from the siblings themselves. Sampling criteria for this study ensured that informants had the necessary experience to provide data relevant to the research question. The researcher's knowledge of and experience with children and their families experiencing critical illnesses as well as the personal experience of having a child with a brain injury has strengthened this study. This provided theoretical sensitivity when interviewing, coding and analyzing data and formulating the theory.

Limitations

A qualitative approach was chosen for this research as the study purpose was to describe and gain an understanding of the impact of a child's brain injury on his/her siblings from the emic perspective of the siblings. A limitation associated with a

qualitative study is that findings are not generalizable beyond those participants in the study (Sandalowski, 1986). This lack of generalizability is a limitation of this research.

Retrospective studies are weakened by the informants ability to re-call earlier events. Informants re-call may have been affected by the stressful nature of events immediately following their brother's injury. Important events and perceptions may have been forgotten by the informant over the ensuing years.

The sample was one of convienence, was relatively small, and included a range of developmental stages (ages 7 to 21 years). Parents chose to have their children participate in this study by contacting the researcher and volunteering their children. There is a possibility that the parents who chose to allow their children to participate were ones who believed that siblings could benefit from sharing their experiences, while those that did not chose to participate perceived no benefit for siblings. As well, the population from which the sample was available is relatively small which may have influenced parents' decision not to participate. Parents who did not respond to the letter about the study may have been concerned about the ability of the sibling to remain anonymous.

Some of the children may have been reluctant to express feelings that they felt were negative or socially inappropriate. Several younger informants in the second interview denied negative feelings toward their brother and/or parents that they had expressed in the first interview, until they were reassured that these feelings were normal and similar feelings had been expressed by other siblings. Also, because the questions were open-ended, some of the children had difficulty articulating their responses and I had to use more direct questioning to help them understand the type of experiences that I

wanted to hear about. Gruer and Walsh (1998) state that when interviewing young children it is often necessary to pose direct questions in order to elicit a description of their experiences.

Conclusion

In this chapter, the process of changing lives of siblings following their brother's brain injury has been discussed in relation to relevant theory and literature available regarding siblings of a child with a brain injury as well as other chronic illnesses. Implications for nursing practice, education and research were discussed. Finally the strengths and limitations of the study were examined. Siblings of children who sustain a brain injury are often the forgotten victims of this family tragedy. It is hoped that this beginning grounded theory will provide the impetus for further research from the sibling's perspective into the impact on siblings of living with a brother or sister with a brain injury and demonstrate the importance of assessing and including siblings in the recovery of children who sustain a brain injury.

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Appendix A

Information About the Study

<u>Project Title</u>: The Impact of a Child's Traumatic Brain Injury on His/Her Siblings.

Dear Parent,

My name is Angela Weir and I am a Master of Nursing student at the University of Alberta. I am doing a research study to learn what siblings say about how having a brother or sister who has had a traumatic brain injury [TBI] affects them. I believe this information will help nurses to provide more appropriate care and support to families of children with a TBI.

In the study I would like to talk to siblings age six to eighteen years of age. If you and your child (children) agree to take part in this study, the sibling(s) will be interviewed individually on two separate occasions. The interviews will take place at a time and location convenient for you and your child. Your child will be asked to tell me about what it is like to have a brother or sister with a TBI. Should you agree to allow your child (children) to participate in the study and the child also agrees, I will telephone you to describe the study and answer any questions. I will make arrangements at that time to schedule the first interview. I anticipate the individual interviews will average 30 to 45 minutes for children ten years of age and under and one to one and a half hour for children over ten years of age. Each interview will be tape-recorded.

If you have any questions or concerns please call me at 458-5433. If you would like to have your child (children) take part in this study, please return the enclosed form or call the researcher (Angela Weir) at 458-5433.

Thank you very much for your time.

Sincerely,

Angela Weir, RN, BScN
Graduate Student

Appendix B

Informed Consent Form

Project Title: The Impact Of a Child's Traumatic Brain Injury on His/Her Siblings

Investigator:
Angela Weir, RN, BScN
Faculty of Nursing
University of Alberta
Home Phone: (xxx) xxx-xxxx

Supervisor:
 Dr. Arnette Anderson PHD
Faculty of Nursing
University of Alberta
 Office Phone: (xxx) xxx-xxxx

Purpose of the Study
        The purpose of this study is to gain a better understanding of what it is like for children who live with a brother or sister who have had a brain injury.

Procedure
        Your child will be interviewed twice. The length of the interviews will depend on his/her tolerance. The average interview will take about 30 to 60 minutes. These interviews will take place in your home, at a time that is best for you and the researcher. Only your child and the researcher will be present during the interview. All interviews will be tape recorded and then typed word for word so that the information can be reviewed later. You will be asked to fill in a form with general information about your family. The researcher will use this information from all of the participants to describe the group of siblings in the study.

Risks and Benefits
        There will be no risks to your child by taking part in this study, nor will you or your child benefit directly from this study. Findings from this study may help nurses and other health care professionals to understand how having a brother or sister with a brain injury affects siblings. This in turn may help to develop programs to help brothers and sisters.

Voluntary Participation
        Your child does not have to be in this study if he or she does not want to be. Your child may drop out of the study at any time by telling the researcher or calling her supervisor. Your child does not have to answer any questions or talk about any subject in the interview if they do not want to. If your child experiences any painful memories and/or feelings during the study a counselling referral can be arranged. Taking part in this study or dropping out of this study will not affect your child's future care.

Confidentiality

Neither your name nor your child's name will appear in this study.. A code number will replace your names and any other identifying material on the typed interviews and notes. All interview records will be kept in a locked cabinet. Consent forms and code lists will be kept in another locked cabinet. The researcher will destroy tapes and consent forms after seven years. Interview information may be used for other research in the future if the researcher receives approval from an ethics review committee.

Quotes from the interviews may be used in reporting these findings, but your child's name or any material that may identify your child or your family will not be used.

You may call the researcher, Angela Weir, or her supervisor, Dr. Arnette Anderson about any questions or concerns.

Consent

I,_____, have read this information and agree to allow my minor son/daughter_____ to be in this study. My questions about the study and my child's part in it have been answered to my satisfaction. I am aware that a counselling referral can be arranged if my child becomes upset during the study. I have crossed out any part of this form to which I do not agree. I have been given a copy of this form to keep. I understand that if any information about the abuse of someone under 18 years of age is told to the researcher during the study, it will be discussed with the parents. The researcher is under legal obligation to report this information to Family and Social Services.

_____   _____

Signature of Parent   Date

_____   _____

Signature of Researcher   Date

If you wish to receive a summary of the study when it is finished, please complete the next section:

Name: _____

Address: _____

_____

Appendix C

Participant's Assent Form

<u>Project Title</u>: The Impact of a Child's Traumatic Brain Injury on His/Her Siblings.

I, _____ state that I am _____ years of age and wish to take part in the study being done by Angela Weir RN, BScN.

The purpose of the study is to learn more about what it is like to have a brother or sister who has a brain injury.

I will talk to Mrs. Weir, two times. Each talk will be for about one hour and what I say will be tape recorded.

No one but Mrs. Weir and her teacher will know what I say.

I may be asked to draw a picture of my family.

No one is making me do this, and I can stop talking at any time if I want to.

If I have any questions about the talk, I can ask my parents or Mrs. Weir.

The answers will be used to help nurses and doctors learn about what it is like to have a brother or sister with a brain injury.

_____   _____

Signature of Participant   Date

_____   _____

Signature of Researcher   Date

Appendix D

Demographic Data

Code Number _____

1. Age of mother_____ Age of father_____

2. Marital status
    Single _____ Married _____ Common-law _____ Separated _____ Divorced _____

3. Indicate the highest level of education completed
    mother _____ father _____

4. Employment status
    Of mother _____ Full-time, _____ Part-time, _____ Not employed

    Of father _____ Full-time, _____ Part-time, _____ Not employed

5. Gender of child with the brain injury _____ Male, _____ Female

6. Present age of child with the brain injury _____

    Age at time of the brain injury _____

    Level of impairment as a result of the brain injury Mild____ Moderate ____ Severe ____

7. Age of sibling in the study. _____

    Grade in school. _____

8. Birth date of each child in the family

    a). _____   d). _____   c). _____

    d). _____   e). _____   f). _____

8. Total yearly family income

    a).$1 -$19,999 _____, b).$20,000 -$49, 999 _____, c).$50,000 -$79,999 _____,

    d). $80,000 -$99,000 _____, e). $100,000 and above _____.

Appendix E

Samples of Probing Questions for the Initial Interview

Note: In the questions following, X refers to the brother or sister with the traumatic brain injury.

Tell me how your friends reacted after X's brain injury.

Tell me how things were for you after X's brain injury.

Tell me about your family since X's brain injury.

Tell me how things are for you at home since X's brain injury.

Tell me how you felt after X came home.

Tell me about any changes in your activities since X's brain injury.

Guiding questions used in subsequent interviews depended on data analysis following the initial interview.